MATERIAL ON HIV/AIDS

SENT BY

MEDICAL MISSION INSTITUTE

AIDS AND INTERNATIONAL HEALTH DEPARTMENT

SALVATORSTR. 22

D-97074 WÜRZBURG

GERMANY

December 1997

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TO ALL RECIPIENTS OF LITERATURE PARCELS

18. November 1997

Dear friends,

Re: Literature Parcel 1997/2

The second literature parcel for 1997 arrives later than usual; the reason for this delay will be explained at the end of this letter. As you see from the list of items contained in this parcel we have again included a wide selection of papers on different aspects of HIV/AIDS related issues.

„AIDS prevention: a challenge to Catholic Moral Tradion" by John Fuller, a Jesuit and medical practitioner looking after PLWAs, and „The Impact of HIV/AIDS and the Churches' Response", a statement adopted by the World Council of Churches after a lengthy study process, are important reflections on Christian responses to the challenges of HIV. They are supplemented by the paper „Community and Pastoral Responses to AIDS in South Africa", which addresses problems and proposes approaches which are relevant in countries and regions far beyond Southern Africa.

Two papers on tuberculosis deal with the growing resistance against common anti-TB drugs and with the importance of TB for children and the diagnostic difficulties encountered. - We included a WHO publication on „The Implications of Antiretroviral Treatments" - not because we expect that these treatments will become available to patients living in your areas but in order to give you a comprehensive background to the very complex issues of these treatment possibilities and to enable you to answer to questions which may be put to you in this context.

Among the other papers we want still to draw your attention to „Monitoring and Evaluation", which is Chapter 6 of a very worthwhile book with the title: „HIV prevention and AIDS care in Africa" by J. Ng'wesheni et al., ISBN 90 6832 108 0, published by the Royal Tropical Institute in Amsterdam. It is a practical source book for a wide range of target groups on district, national and NGO level and an excellent example of making the participative community approach a reality. It is obtainable from bookshops or from: KIT Press, Royal Tropical Institute, P.O. Box 95001, 1090 HA Amsterdam, The Netherlands. Price approx. 49.- Dfl.

We also want to draw your attention to a publication „Working with Young People on Sexual Health and HIV/AIDS" which is available from AHRTAG, London, and focuses on relevant HIV-awareness creation activities (For the address please consult the „AIDS action" Newsletter).

As usual we have included the two latest issues of AIDS action. The one on „HIV and safe, healthy sex" seems not to have been funded by CAFOD, Misereor etc. as is normally the case - possibly due to the content of this issue with its narrow focus on medical aspects of reproductive health. We are missing any reference to value aspects of sexuality. However, after some discussion in our group, we agreed to leave the decision to our partners, if they wish to make use of the information in issues 36/37 1997 of AIDS action.

Not every paper sent will be relevant to the work of all our addressees; we appeal again to you to pass these items on to others who may benefit from them. Please act as a multiplicator for as many people as possible in respect of all new and updated information received by you.

The delayed dispatch of this literature parcel was due to the fact that we were not sure for a long time about the future of our work in the coming years. It is now clear that we will have to curtail the distribution of literature from 1998 onwards. This is due to the impending restructuring of our department, the taking on of additional tasks and the reduced financial provision for the purpose of literature acquisition. However, we hope to be able to send you one literature parcel annually, probably in mid-year. Besides, we shall continue to meet individual requests for specific items of information on HIV/AIDS and related issues in as far as this will be possible. As usual, your comments on the usefulness and appropriateness of the literature sent will always be welcome.

With our best wishes for your endeavours in preventing the spread of HIV and caring for the affected

Clemens Obergfell Klemens Ochel Gesine Ruppert-Mann Traudl Solleder

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December 1997

AMERICA

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AIDS PREVENTION:

A CHALLENGE TO CATHOLIC MORAL TRADITION

JON FULLER

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AIDS Prevention:
A Challenge to the Catholic Moral Tradition

Just as the threat of nuclear weapons prompted re-examination of our thinking about war, the expanding threat of AIDS requires re-evaluation of our posture toward the prevention of H.I.V. infection.

By JON FULLER

EVEN THE MOST CASUAL OBSERVER of H.I.V./AIDS in the popular press cannot help but notice the dramatic change in tone that has accompanied stories reported during the past several months. For example, The New York Times Magazine's cover story on Nov. 10, "When Plagues End," was echoed by Newsweek's Dec. 2 cover story, "The End of AIDS?" These and many other essays highlight the promise that new, more powerful drugs offer to H.I.V.-infected individuals. Indeed, preliminary success with these agents has prompted some researchers to speculate about the possibility of completely eradicating H.I.V. from infected persons.

Fortunately, most reports have also been careful to note several important caveats about the new drugs: 1) Since even the longest-running trials are barely more than a year in length, the duration of their benefit is unclear; 2) these compounds can be extremely toxic and are not effective in everyone; 3) their annual price tag (when taken in combination) of up to $25,000 makes them accessible only to a limited number of infected persons living in industrialized countries. However, despite these disclaimers, I have a growing fear that as a result of such sensational headlines many Americans will breathe a huge sigh of relief, more than happy to regard as "cured" an epidemic that has prompted deeply ambivalent feelings since its beginning.

The fact remains that more than 90 percent of the world's infected persons will have no access to these drugs, as annual per capita budgets for all health care needs are less than $5 to $10 in many developing countries. We now know that, given time, progression to an AIDS diagnosis occurs in virtually all untreated H.I.V.-infected persons. In the absence of an effective preventive vaccine (not likely to be developed for at least five to

JON FULLER, S.J., M.D., is assistant director of the clinical AIDS program at the Boston Medical Center and was founding president of the National Catholic AIDS Network. This essay is based on a talk given at the St. Louis University Health Sciences Center on Oct. 22, 1996.

GRAPHS COURTESY OF THE AUTHOR

10 years), primary prevention is the sole response that offers protection to those most threatened: the poorest and most marginalized members of society.

I would argue that as a church we have dedicated relatively little attention to the complex challenge of H.I.V. prevention, perhaps because we have not fully appreciated the impact the epidemic is having on those for whom we bear special responsibility: minorities, the poor, women and children. I would further argue that a careful assessment of the facts calls us to a paradigm shift in our approach to analyzing H.I.V. prevention questions. In order to develop this argument I will first summarize the current state of H.I.V./AIDS, then discuss the relative inattention that has been given to the epidemic itself. After reviewing objections to H.I.V. prevention programs that have been raised by some church leaders, I will argue that just as the threat of nuclear weapons prompted a re-examination of our way of thinking about war, so now the expanding threat of AIDS requires a re-evaluation of our posture toward the prevention of H.I.V. infection.

The number of Americans already infected is nearly twice the number of Americans who have died during all major wars fought since this country was founded.

H.I.V./AIDS in the United States.

Since the epidemic was first recognized in 1981, between 900,000 and 1.2 million Americans are estimated to have been infected with human immunodeficiency virus (H.I.V.), the causative agent of AIDS. As a result, as of June 1996 more than 540,000 Americans had been diagnosed with AIDS and more than 330,000 had died. The epidemic's greatest impact has been on young adults, with AIDS now counted the number three killer of young women aged 25 to 44 (Fig. 1) and the leading killer of young black women (not shown). Among men aged 25 to 44 AIDS is the number one killer (Fig. 2), and (because of such high rates in men) in this age group AIDS is ranked the leading killer of men and women combined.

Because the epidemic's greatest impact has been on young adults, AIDS takes a greater social toll than other fatal diseases that have their onset later in life. For example, although by 1991 AIDS was ranked ninth as the cause of death for all age groups combined, it ranked fifth in terms of the number of years of life lost before age 65. This early death translates into enormous social and economic costs, as young adults are stricken during some of their most productive years and at a time when they are bearing and rearing children. It is anticipated that by the year 2000 AIDS will have caused 125,00 to 150,000 American children to become orphans, with 30,000 to 50,000 of these living in New York City alone.

Beneath the surface of these statistics are deeply disturbing trends regarding the disproportionate burden of disease and death being borne by communities that are already marginalized and vulnerable. Although African Americans and Latinos together constitute 21 percent of the U.S. population, they account for 47 percent of AIDS cases reported in 1995 among men, 76 percent of cases among women and 81 percent among children. Among U.S. women diagnosed with AIDS, only half have finished high school and more than three-quarters have an annual income under $10,000.

As shown in Figure 3, these trends toward an over-representation of AIDS cases in minority communities are only worsening over time. Deaths from AIDS reflect the same pattern, with an AIDS mortality rate in 1994 that was 4.5 times higher in black men than in white men, and 8 times higher in black women than in white women (Fig. 4).

Over time, gay and bisexual men have constituted a gradually decreasing proportion of total cases, declining from 66 percent in 1985 to 42 percent of those diagnosed in 1995. H.I.V. transmission through injection drug use has now become one of the dominant engines driving the epidemic in this country, accounting for 26 percent of all cases in 1995, up from 16 percent in 1987. If one adds to the H.I.V. transmissions directly attributed to drug use those that occur from intercourse with a drug user or that pass to a child from a mother who uses drugs or was infected by a drug user, injection drug use accounts for 35 percent of all AIDS cases reported in 1995 and for 42 percent of 1995 cases among children.

The Global Epidemic.

An estimated 28 million persons worldwide have become H.I.V.-infected, with 6 million already dead from AIDS. Between 8,000 and 13,000 new infections are estimated to take place each day—up to 540 every hour—96 percent of which are occurring in developing countries. Approximately half of all infections (more than half in some areas) are now occurring among women. Recent estimates project that by the end of the year 2000, 60 to 70 million adults could be infected worldwide, with more than 70 percent attributed to heterosexual intercourse. Those who are becoming infected are largely persons who

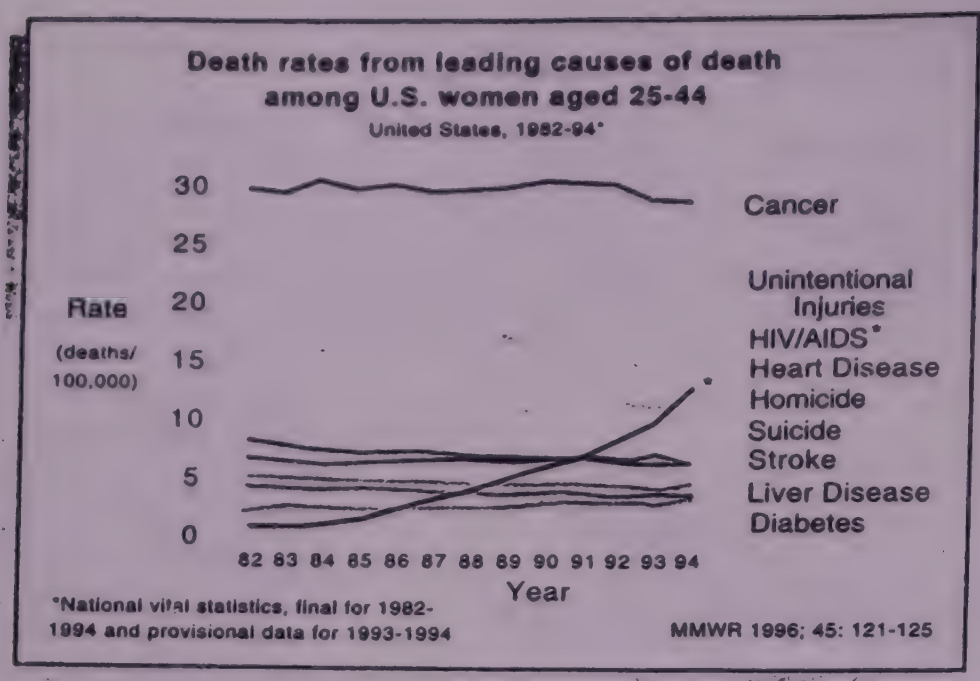

FIGURE 1.

are inexperienced, have little power or both; the majority are 25 years of age or younger.

For several reasons women may be particularly vulnerable to the epidemic. Especially in developing economies, their inferior economic status may compel women to engage in commercial sex activity as a means of survival; this places them at high risk for becoming infected. For a number of social and biological reasons younger women are particularly vulnerable to H.I.V. and have a peak H.I.V. incidence between the ages of 15 and 25, 10 years earlier than for men.

Africa has borne the lion's share of the global epidemic for many years. Although Africa has less than 10 percent of the world's population, it has counted more than 60 percent of global H.I.V. infections (Fig. 5). In some sub-Saharan countries 20 percent to 30 percent of sexually active adults have become infected, with dramatic negative consequences for life span and economic development.

Africa's dominance, however, may be eclipsed within just a few years. The recent spread of H.I.V. within Asia is responsible for the fact that this highly populated region is already responsible for 22 percent of the world's infections. In Thailand, Myanmar (formerly Burma) and Cambodia, H.I.V. infection rates already meet or exceed 2 percent (compared with 0.5 percent in the United States), and the 0.3 percent incidence observed in India accounts for 3 million infections in that country alone. An additional characteristic that makes H.I.V.'s incursion into Asia especially worrisome is the already high prevalence of tuberculosis in the region. H.I.V. is the most potent activator of latent TB yet identified, and AIDS has already caused a significant increase in TB deaths due to co-infection with H.I.V.

In addition to perinatal transmission, children in many developing countries are also at risk of becoming H.I.V.-infected through coerced participation in prostitution. H.I.V. prevalence among children is 35 times higher in developing countries than in the industrialized world, with 1.3 million children H.I.V.-infected and 300,000 dead from AIDS—85 percent in sub-Saharan Africa. During 1995 an additional 500,000 children were infected—more than 1,300 per day—97 percent in Africa and Southeast Asia. An additional 9 million children—90 percent in Africa—have become orphans because of H.I.V./AIDS.

In summary, since its recognition in 1981 AIDS has grown from epidemic to pandemic proportions. Accounting for more than 1.5 million deaths and 3 million new infections annually, AIDS is now responsible for as many deaths as malaria and can be counted as one of the globe's leading infectious killers. According to the recently published 10-volume *Global Burden of Disease Study,* by the year 2020 H.I.V.'s ranking is estimated to move from its current 28th place to 10th place. In the United States more than 95 percent of AIDS cases occur in marginalized populations: minority communities, injection drug users and gay or bisexual men. In the rest of the world, children and poor women—including monogamous married women whose husbands frequent commercial sex workers—have the least capacity to reduce their risk of becoming infected.

Losses From AIDS and Wars.

Given the enormous impact of AIDS in this country and worldwide, what place does the epidemic have in our communal consciousness? I judge this to be a very important question, especially when we recognize that AIDS is a new cause of death, is a preventable cause of death and is—since humans are the only natural host for H.I.V.—a potentially eradicable disease, like smallpox.

In order to answer this question in the American context,

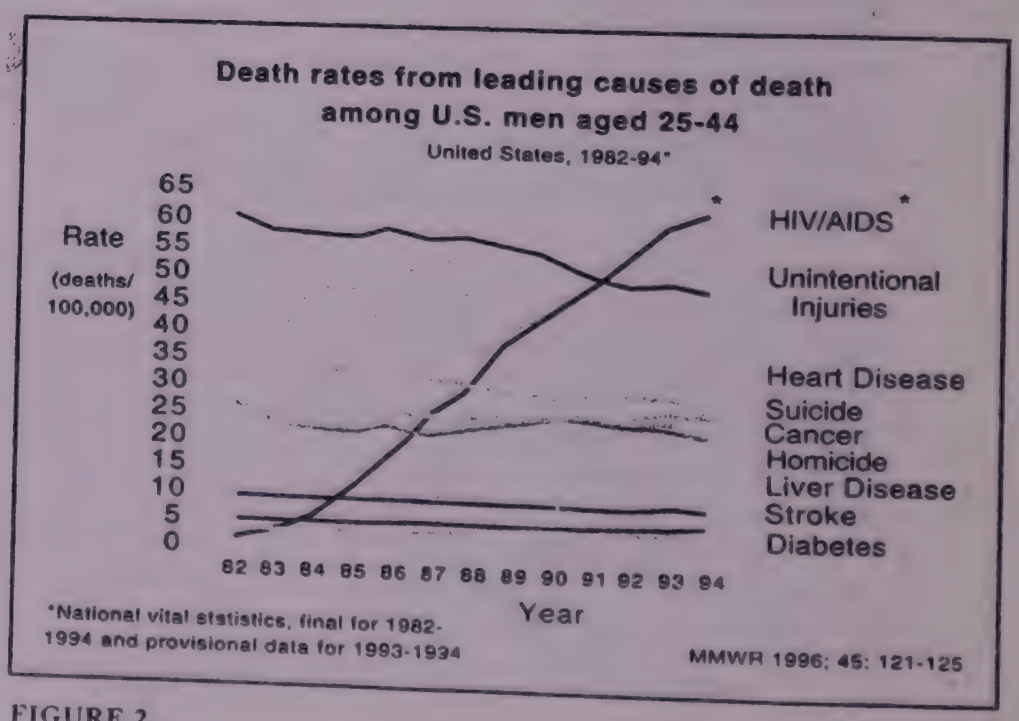

FIGURE 2.

I have been interested in comparing our AIDS experience with other historical events that have also taken large numbers of lives. As our country marked the anniversaries of several World War II and Vietnam War events during the last few years, I wondered how wars and the epidemic compare both in their human cost and in the public response that developed to combat them. I was particularly interested in comparisons with Vietnam not only because of that war's relatively recent date, but also because of the public reaction that eventually led to that war's end and the cessation of killing.

During the 1970's, Vietnam was literally brought into our living rooms by way of the evening news. Night after night we saw the day's casualties tallied on our television screens as body bags were unloaded from U.S. cargo planes. Gradually, when it became clear that this tragic loss of life was not only unnecessary but also unfruitful, public opinion galvanized against the war. The most powerful voices of the antiwar movement for me were not militants and radical groups, but ordinary citizens: families and friends who had experienced first-hand the loss of loved ones in Vietnam. These were not extremists; they were witnesses to a preventable loss of life who said "no more!"

When I compared the numbers, I was stunned. By any measure, the loss of 58,000 lives during the Vietnam War was a terrible cost, and its impact on the country's psyche and public policies was enormous. Yet the number of U.S. lives lost to AIDS far exceeds those lost in Vietnam (by a factor of five), and outstrips even those from World War II. In fact, nearly as many lives are now lost each year to AIDS as were lost during the entire seven years of the Vietnam conflict (Fig. 6).

Also remarkable is a comparison between the number of American lives lost from all U.S. wars and the total number of Americans estimated to be infected with H.I.V. As can be seen in Figure 6, the number of Americans already infected—estimated at up to 1.2 million—is nearly twice the number of Americans who have died during all major wars fought since this country was founded.

Even more startling than a comparison of the numbers, however, is the different position the AIDS epidemic has in our collective consciousness at the present time in comparison to the place Vietnam or World War II had. It is my impression that for most Americans today, H.I.V./AIDS is not even on the list of the most pressing issues we face. Was AIDS included in any debate in this election year, or in anybody's platform? The only mention I remember was the suggestion that H.I.V.-infected illegal immigrants should not receive medical care. This general lack of interest may be related to the fact that those who are most affected have little voice in the dominant culture, and that no one is stepping forward to raise an effective alarm about this tragic loss of life.

Have there been analogous situations in which extant teaching was simply not adequate, for which novel reflection and development of the tradition had to occur?

The Church's Response.

How have we responded? In many places in this country and around the world the church has been an important provider of compassionate and non-judgmental pastoral and clinical care, and has also been an outspoken critic of discrimination and judgment against H.I.V.-infected persons. But in addition to our response to already-infected individuals, there is a second important area in which our experience is more complicated: that of primary prevention of H.I.V. transmission.

The church, in concert with public health approaches, has consistently advised that the most effective way to protect oneself from becoming H.I.V.-infected is to avoid high risk activity. More specifically, the church has advocated abstention from drug use and approves intercourse only with one's spouse in the context of marriage.

But what if high risk activity occurs despite warnings to the contrary? In this circumstance, public health officials have supported condom use and needle exchange programs as effective means of diminishing the risk of H.I.V. transmission. These approaches, however, have not generally been regarded favorably by the church, and as a result some have viewed the church as actually contributing to the spread of the epidemic rather than helping to contain it.

While it is not my intention here to argue an ethical case either for or against condom use or needle exchange programs, I would like to explore some of the objections that have been made, share some new information relevant to these objections, then raise a number of concerns regarding the level of our resources and attention that are devoted to an ongoing analysis of these questions.

Condoms to Prevent Sexual Transmission.

In their 1989 letter on the AIDS epidemic, "Called to Compassion and Responsibility" (Origins 19 [1989] 421-34), the National Conference of Catholic Bishops objected for a number of reasons to programs that promote the use

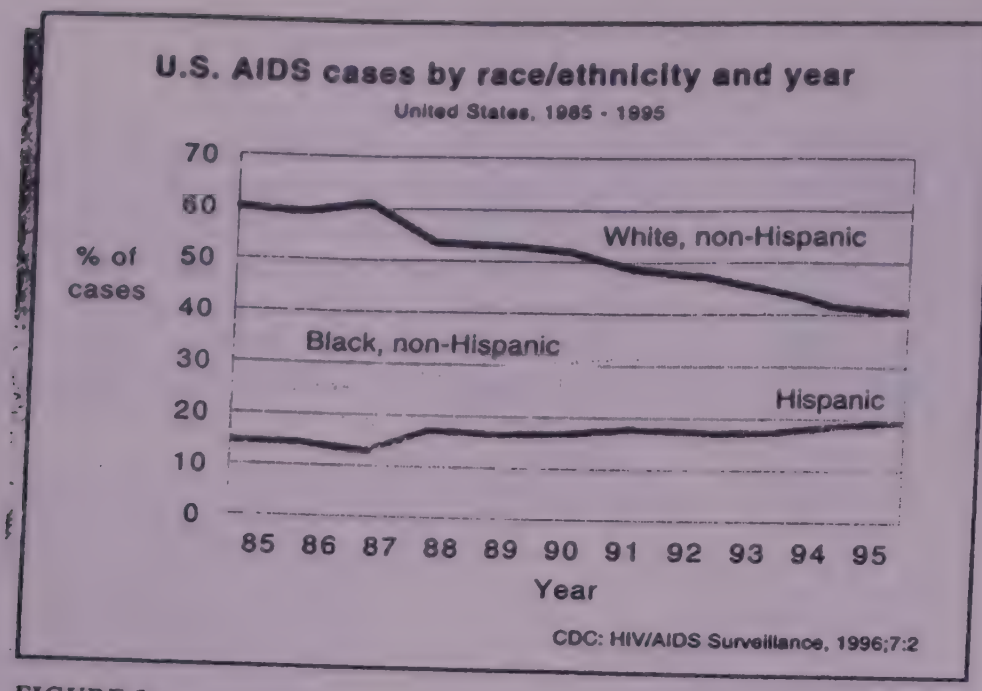

FIGURE 3.

of condoms. In addition to a concern that this approach "means in effect promoting behavior which is morally unacceptable," the bishops were also concerned with questions of efficacy. They noted that the promotion of condoms is "poor and inadequate advice, given the failure rate of prophylactics and the high risk that an infected person who relies on them will eventually transmit the infection in this way."

At the time their letter was written, it was certainly reasonable to look to the available literature on contraception to determine how effective condoms might be in preventing H.I.V. transmission. Since then, however, several sources of data have become available that more specifically assess the capacity of condoms to reduce H.I.V. transmission in real-life situations.

The first is a study of heterosexual couples who were discordant for H.I.V. infection, i.e., one member was infected and one was not (De Vincenzi, New England Journal of Medicine 331 [1994]:341-46). This two-year observational study evaluated the number of H.I.V. infections that occurred as a function of the regularity with which condoms were used. Among 256 couples who formed the study set, three groups were defined retrospectively based on their reporting of condom use. Eleven couples refused to give information about their sexual behavior; no infections occurred in this group. Among 121 couples who reported inconsistent condom use, 12 infections occurred, whereas among the 124 who reported consistent use there were no infections despite an estimated 15,000 acts of intercourse.

The second and third data sets come from public health initiatives that have shown remarkable progress in diminishing the rate of new infections in two developing countries with severe H.I.V. burdens.

The first case is that of Uganda, where H.I.V. infection rates among adults as high as 30 percent make it one of the most heavily affected countries in the world. Each year 150,000 to 200,000 Ugandans die of AIDS—nearly 1 percent of the country's population—with hundreds of thousands of children orphaned as a result. Given the country's wrenching poverty after years of civil war and the fatalistic attitude toward AIDS, some planners had despaired that any intervention could modify the behavior of young people at highest risk.

But recent studies have reported dramatic changes in behavior and infection rates, with trends toward fewer partners and an increased use of condoms. For example, at the Nsambya Prenatal Clinic in a suburb of Kampala, the H.I.V. infection rate among first time mothers dropped from 29.9 percent in 1993 to 16.8 percent in 1995. At the Mulago Hospital in central Kampala, between 1989 and 1993 the infection rate among pregnant women below the age of 17 fell from 23 percent to 8 percent (J. C. McKinley, The New York Times, April 7, 1996, p. A1).

Many researchers have attributed these dramatic behavioral changes to intense educational efforts that promote abstinence and faithfulness but also discuss condom use. I had the opportunity to spend a month in Uganda earlier this year and can attest to the size of the public health educational program. As soon as one drives away from the airport, the emphasis placed on AIDS prevention becomes evident on billboards that spread the message: "Protect yourself: condoms, abstinence, faithfulness."

The second case is Thailand, where the epidemic has risen from virtually no infections in 1985 to the current situation, in which 2 percent of the population is infected. The situation in Thailand has been especially challenging because sex tourism is a major Thai industry, and because many Thai married men frequent commercial sex workers.

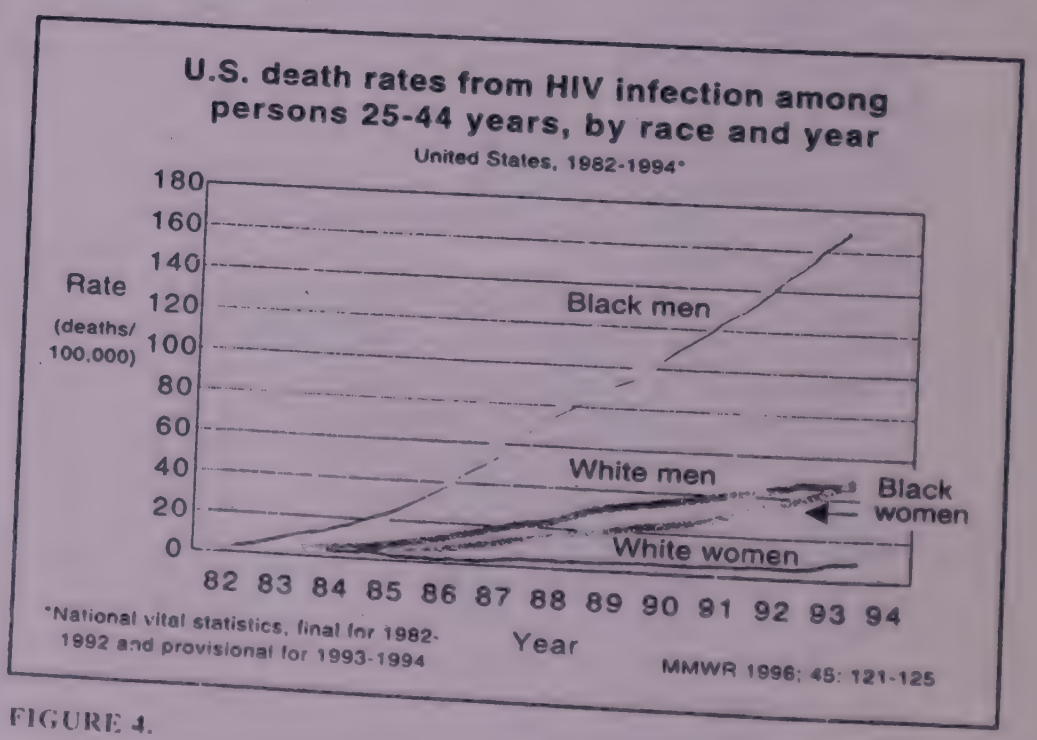

FIGURE 4.

However, a concerted effort by the Government, known as the 100 Percent Condom Campaign, has dramatically reduced the incidence of sexually transmitted diseases and new H.I.V. infections. Between 1989 and 1993 the use of condoms by commercial sex workers rose from less than 50 percent to more than 94 percent and was accompanied by a reduction in sexually transmitted diseases—taken to be a surrogate marker for new H.I.V. infections—from 6.5 per 1,000 to 1.64 per thousand (W. Rojanapithayakorn, Tenth International Conference on AIDS, 1994, abstract 478C). In a subsequent effort to confirm the impact of this program on the spread of H.I.V. itself, a second study evaluated H.I.V. prevalence trends between 1991 and 1995 among 21-year-old army recruits from Northern Thailand.

H.I.V. prevalence rates had been stable at 10-12 percent in the 1991 and 1993 cohorts, but dropped to 6.7 percent in 1995, a highly significant change. The point is that the H.I.V. prevalence rate descended to only 0.7 percent in men who had reported contact with commercial sex workers only after 1992 (K. E. Nelson, Eleventh International Conference on AIDS, 1996, abstract We. C. 3521). A third study analyzing national trends in condom use and H.I.V. prevalence data concludes that this campaign has already saved two million Thai lives (N. J. Robinson, Eleventh International Conference on AIDS, 1996, abstract Mo. C. 904).

Needle Exchange Programs.

Developing effective strategies to prevent H.I.V. transmission among drug users has been a particularly daunting challenge, since by definition being addicted implies a diminished freedom to abstain from drug use. In addition, even when individuals are ready to enter into drug treatment, only a fraction of the treatment program slots needed at any given time are available. Obviously recovery from addiction represents the most desired long-range outcome, but until it is achieved the non-availability of sterile injection equipment places injectors, their sexual partners and, in the case of pregnant women, their developing fetuses at risk of becoming infected. For these reasons needle exchange programs have been advocated by public health authorities in many countries and cities as a way to prevent transmission while recovery is pursued as a long-range goal.

Again in their 1989 letter, the U.S. bishops raised several important moral and practical questions regarding these programs. They wondered, for example, whether more drug use might result while fewer drug users seek treatment, and whether poor monitoring could lead to increased spread of H.I.V. through contaminated needles.

Since their letter, numerous studies from this country and abroad have become available regarding the safety and efficacy of needle exchange programs. In addition, a meta-analysis of studies of needle exchange and bleach distribution programs was recently published by a panel of the National Research Council and the Institute of Medicine in order to respond to the question of Congress: Is there sufficient evidence in support of needle exchange programs to justify lifting the current ban on Federal dollars to support them? The panel found: "There is no credible evidence to date that drug use is increased among participants as a result of programs that provide legal access to sterile equipment.... The available scientific literature provides evidence based on self-reports that needle exchange programs do not increase the frequency of injection among program participants and do not increase the number of new initiates to injection drug use."

With the dawn of the AIDS epidemic, the moral implications of sexual intercourse and injection drug use have changed in as significant a fashion as did modern warfare in 1945.

Their report concluded that "Needle exchange programs should be regarded as an effective component of a comprehensive strategy to prevent infectious disease," and recommended that "the Surgeon General [should] make the determination...necessary to rescind the present prohibition against applying any Federal funds to support needle exchange programs" (National Research Council and Institute of Medicine, "Preventing H.I.V. Transmission: The Role of Sterile Needles and Bleach," National Academy Press, 1995).

None of the studies I have cited suggests that condom use or needle exchange programs in themselves are the answer to the AIDS epidemic. However, they do demonstrate that these approaches can be part of the solution, that in real life situations they have significantly prevented H.I.V. transmission and have saved many human lives.

Prevention and the Church.

Having now reviewed the status of the epidemic and a number of recent studies regarding the efficacy of various prevention efforts, we come to the central question: How are these data affecting our response in the area of preven-

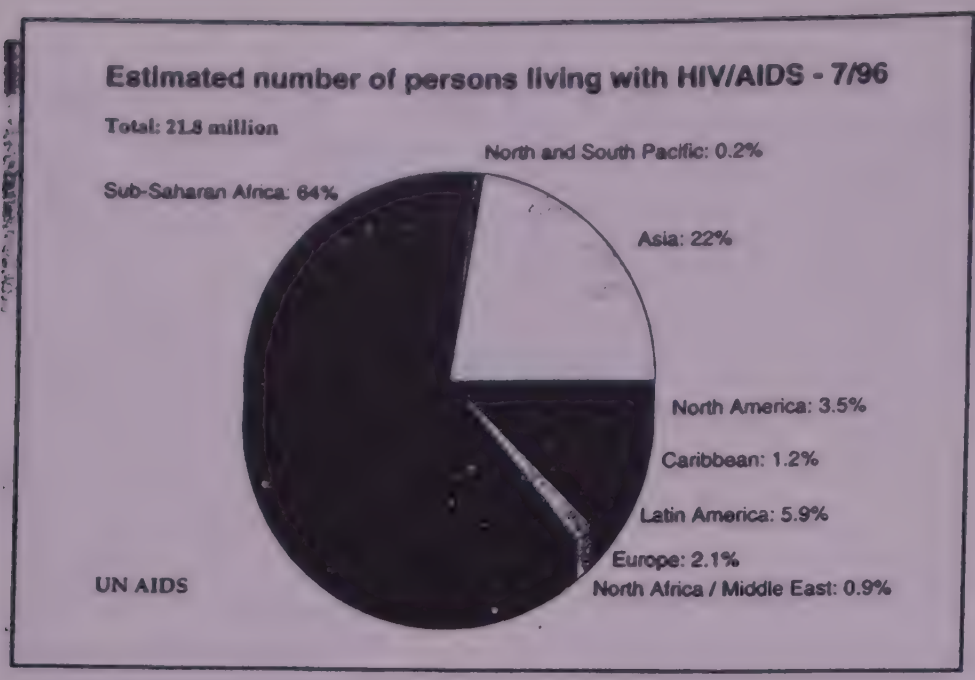

FIGURE 5.

tion? What impact have they had on the discussion of these topics within the church?

Let me answer by asking: When was the last time you read an article in a Catholic periodical, whether popular or professional, that seriously attempted to engage the moral issues involved in needle exchange or condom education programs? How many individual philosophers, theologians, historians or their academic societies are you aware of that even consider these topics to be of interest and importance?

Unfortunately, I think the answers to these two questions are, respectively, "almost never" and "almost none." A few moral theologians and ethicists (including James Drane, James Keenan, S.J., and John Tuohey in this country, Enda McDonough in Ireland and Kevin Kelly in England) have written on these questions, but they are still quite solitary voices.

I have puzzled over this relative silence and inattention in the face of an expanding global calamity and find myself asking: "What's wrong with this picture? How can a church that is so deeply committed to social problems, to health care, to the protection and sanctity of life and to the defense of the poor, have given so little attention to the prevention crisis in which we find ourselves?" Do we fully appreciate that the moral and social implications of sexual intercourse and injection drug use have changed? These behaviors are now potentially lethal to individuals and society in a way that has never been true before. The very terms of the discussion have been altered, and yet I wonder if we are not presuming to respond to the questions we face using pre-AIDS analyses, in which quite different risks and underlying assumptions were operative.

Lessons From History.

Is there any previous experience to which we can turn for insight into the current crisis? Have there been analogous historical situations in which the extant teaching was simply not adequate, for which novel reflection and development of the tradition had to occur? We know, in fact, that this is how our tradition has grown and developed since its earliest years, beginning with the question of gentile circumcision. This is particularly obvious in the responses developed in the course of the Christological controversies of the early church.

In more recent history one might count as examples such events as the Industrial Revolution, the advent of labor unions, the rise of socialism, the development of techniques for genetic manipulation and the detection of inherited disease, and the possibilities of in vitro fertilization. However, I think there is one event in particular that has remarkable parallels to the AIDS situation and may provide helpful insights for us as we try to make our way forward. That event was the invention of the atomic bomb and the nuclear arms race it triggered.

Until the advent of the cold war, the long and somewhat complex tradition of the just war theory had guided the church through centuries of reflection regarding the moral use of aggressive force. With the development of nuclear arsenals, however, the ethical tradition was faced with a novel challenge. The entire context and meaning of waging war had changed, making it impossible to apply the just war theory in a straightforward way. Suddenly, critical elements of that theory were no longer applicable; concepts such as "use of proportionate means" and "protection of non-combatants" had become meaningless. This called for a re-evaluation of moral maxims in the context of novel and problematic cases.

It is especially revealing that in their landmark pastoral letter on war and peace, "The Challenge of Peace: God's Promise and Our Response" (1983), the U.S. bishops were quite conscious of the need to approach the tradition anew. They repeated the position of Vatican II's "Constitution on the Church and the Modern World," which said, "It is nec-

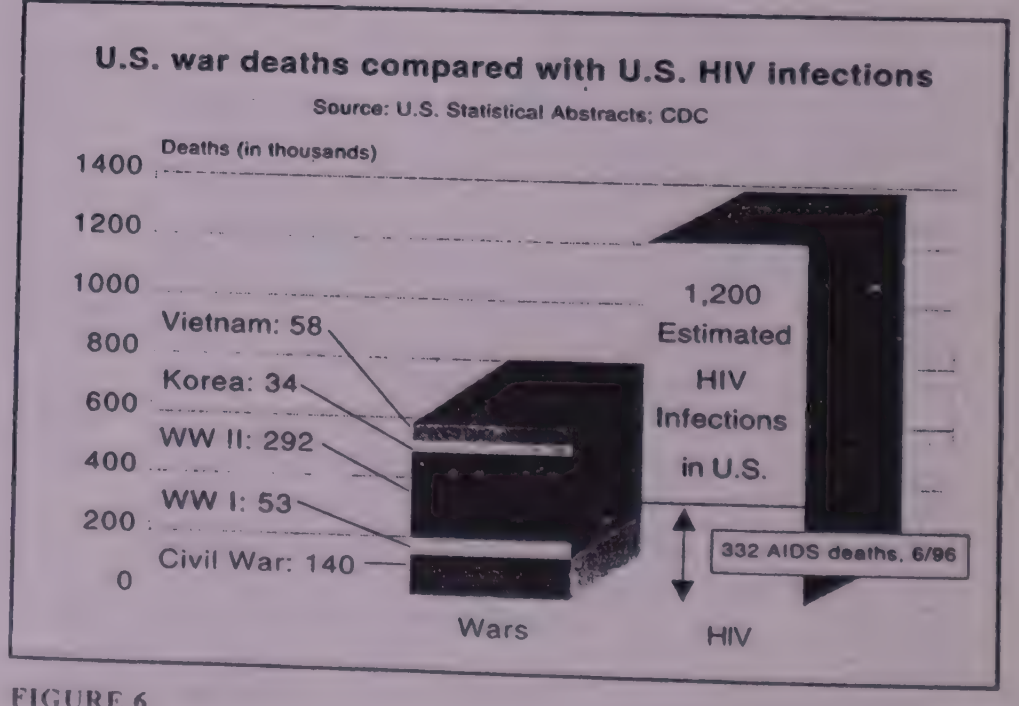

FIGURE 6.

essary to undertake a completely fresh appraisal of war," and in their own words made the need for this reassessment quite explicit: "No previously conceived moral position escapes the fundamental confrontation posed by contemporary nuclear strategy.... The task before us is not simply to repeat what we have said before; it is first to consider whether and how our religious-moral tradition can assess, direct, contain and we hope, help to eliminate the threat posed to the human family by the nuclear arsenals of the world."

As we know, the bishops judged that possessing nuclear weapons for the sake of deterrence was a tentatively tenable moral option. The principle they appear to have invoked was that of tolerating the lesser evil. That is, while they found the development of nuclear weapons reprehensible in itself, given that this had already occurred, the possession of nuclear arms could be morally supported as an interim measure to minimize the clear and present threat of a nuclear holocaust: "In current conditions, 'deterrence' based on balance, certainly not as an end in itself but as a step on the way toward a progressive disarmament, may still be judged morally acceptable." In short, possessing nuclear weapons qualified as a preventive measure.

The point I am making here is not just about the development of a deterrence policy; it is most especially about the reshaping of moral thinking once novel and difficult cases strain the applicability of previously established principles. I would argue that with the dawn of the AIDS epidemic, the moral implications of sexual intercourse and injection drug use have changed in as significant a fashion as did modern warfare in 1945. However, we do not seem to have taken the leap we took when the prospect of nuclear holocaust prompted a thorough reassessment and extension of the just war tradition. In the case of the bomb, the novelty was seen and the relative inapplicability of previous reflection recognized. I would argue that we have not yet seen the analogous implications of AIDS, have not really begun to analyze the difficult moral cases that AIDS presents and have not recognized that an AIDS atomic bomb has already gone off in slow motion, with six million dead and another 22 million awaiting their premature deaths as a result.

Could our responsibility to protect life now justify the use of preventive methods that would otherwise be judged negatively? If behavior—whether voluntary or coerced—is going to occur despite our objections, is the moral evil of those actions increased or decreased by trying to minimize the possibility that such activity could lead to the loss of human life through the transmission of H.I.V.? It may be helpful in this regard to note that the Jewish ethical principle of *piquuach nephesh* ("saving an endangered life") holds that all prohibitions—save those against idolatry, murder and incest—may be abrogated in order to preserve a human life.

It seems to me that we need to begin the difficult work of identifying the hard cases and exploring, through a thorough understanding of each situation, what possibilities the tradition might offer, given the newly lethal outcomes of certain widely practiced behaviors.

Who can best identify and characterize the cases in order that this moral reflection might proceed in earnest? Obviously this process will require specialized input from those with knowledge and experience of the epidemic, including its impact on individuals and communities. In my mind, since we are talking about dialogue with the Catholic tradition, this is an area in which Jesuit universities with medical centers might play a unique role, especially when one considers that four of the five Catholic medical schools in this country are part of Jesuit universities. Medical, nursing, public health and social work faculties know the epidemic scientifically and know its human face. But they are also part of larger institutions whose vision is based on a preferential option for the poor and marginalized—those most affected by H.I.V./AIDS. These institutions can also draw upon experts in history, philosophy and theology who know how to interrogate the tradition and who are familiar with and know the limitations of casuistry and other ethical methods.

Conclusion.

When the pastoral letter on war and peace was written in 1983, the world had the benefit of nearly 40 years' reflection on the dawn of the nuclear age. The bishops pointed out, "We have encountered this terror in the minds and hearts of our people—indeed we share it." In contrast, the world has known AIDS for only 15 years, and not everyone has experienced the devastation it causes nor come to appreciate the extent to which it increasingly burdens the poor—those with the least power to reduce their risk of becoming infected. It seems to me that our obligation is to make this experience known, to be the voice of those who have no voice, to bring these new and difficult cases to multidisciplinary scrutiny.

I do not presume to know where an adequate review of these questions will lead us, but it does seem that we have only begun to apply our resources and experience to an analysis of the unique questions and challenges that are becoming larger as H.I.V. spreads in the world. My intention in this essay is to issue a plea to all, in the words of Vatican II, to read and respond to the "signs of the times" in order to assist the church in discerning how we can be faithful to our tradition and thus faithful to our responsibility to protect life.

The church has been criticized by some for its failure to raise an adequate public outcry against the Nazi Holocaust, a cry that might have prevented further loss of life. My hope is that when history reviews the role that our generation of the church played in responding to the devastation of AIDS, comparisons will likely be drawn not to our relative silence regarding the Holocaust, but to the way we were able to recognize the need for a paradigm shift in responding to the threat of nuclear arms. Let us hope that, when the history of AIDS is eventually written, the final judgment on our response to efforts to curb its spread will be that we were part of the solution and not part of the problem. ■

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COMMUNITY AND PASTORAL RESPONSES TO AIDS IN SOUTH AFRICA

by

Gertraud Solleder[1]

According to yet unpublished results of the 1996 HIV seroprevalence survey of women attending antenatal clinics in RSA the prevalence has risen countrywide from an average of 10.4% in 1995 to 14.7% at the end of the past year. It is said that every 5th pregnant women in KZN carries the HI virus and every 4th one in Durban and that altogether approximately 2.4 million South Africans are infected.[2] This means that RSA is rapidly catching up with other countries in the Southern African region, like Malawi, Zambia and Zimbabwe. This shows that the theme of this paper deals with a most important topic, a topic of extreme urgency, a topic which is not only relevant to health but which touches on all aspects of life and future of individuals, families, communites and nations.

The social and cultural background to the HIV epidemic in Southern Africa

Confronted with the escalating almost exlusively heterosexual spread of the HI virus, which affects women in greater numbers and at an earlier age than men, we have to ask ourselves about causes and contributory factors in the socio-economic situation and the cultural background. Major social, political and demographic changes have taken place in all countries of Southern Africa during the last few decades. They have resulted in population displacement, migration and rapid urbanization. Open conflicts in Angola, Mocambique and Namibia, the political struggle in RSA, environmental degradation and natural disasters have led millions to leave their place of residence. Better transport facilities and a growing communication network, increased possibilities for trade, industrial and other development programmes have stimulated the movement of young men and women within and across national borders. Migration and urbanization have led to a high concentration of communities with predominantly male members who are living in overcrowded accomodation, partly of the hostel type, amidst great squalor. Previously adhered to social norms have been abandoned. There is increased participation in commercial sex, particularly within professional groups characterized by mobility; to these belong a.o. truck drivers, traders and military personnel who also have the financial means to pay for it. It is therefore not surprising that it is first the better-to-do people in a population who are affected by HIV but it is the members of the poor majority who are hardest hit. 90% of all HIV infected persons live in developing countries, alone 60% in Subsaharan Africa![3]

According to the World Development Report of 1994 most countries in Southern Africa belong to the group with the lowest average income.[4] RSA, Botswana and Namibia are an exception; but this exception is only a relative one because the overwhelming majority of the population are poor. Poverty means lack of essential things of life, inadequate housing, missing educational opportunities, unemployment, lack of knowledge how to protect oneself against disease and lack of access to health services. Often, families are only able to survive if one or several members earn money through migratory labour. This means for those who live and work elsewhere absence from family and friends, from the familiar environment and the traditional way and norms of life. The absence of personal and social bonds promote liaisons with several partners, not in the least to escape a hostile environment and the lack of recreational facilities. The insecurity of daily life and the ever present threat of criminal activities jeopardize any concern for the dangers of an infection which is not causing illness immediately but only after a number of years: Why should I bother now about dying in a few years - if I may be killed several times before! The possibility to earn money away from one's home may ensure the survival of the family on the one hand and introduce the deadly virus on the other.

Women are particularly threatened by an infectious agent whose mode of transfer they can hardly control. Apart from a higher biological vulnerability, particularly when young, women hold a subordinate position in society, are economically dependent on men and unable to selfdetermine their sexual behaviour. For women who live under difficult circumstances, who have to care on their own for the family, sex is often the only good they can sell in order to get some money for food, for clothing and schooling of the children, for other

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[1] Based on the paper presented by G. Solleder M.D., D.H.S.M., at the Conference of the Association for Clinical Pastoral Education of Southern Africa and the South African Association of Pastoral Work on 21st May 1997 at Groote Schuur Hospital, Cape Town.

[2] Information obtained during the conference from one of the speakers

[3] The Status and Trends of the Global HIV/AIDS Pandemic, July 5-6, 1996, XI International Conference on AIDS, Vancouver

[4] World development Report 1994

necessities of life and for protection in an environment full of dangers. Most important however is the fact that the majority of women are infected by their one partner to whom they themselves are faithful! Even if a woman suspects her husband to be infected she does not dare to refuse sexual intercourse or insist on the use of a condom for fear of being assaulted or chased away; traditionally the husband may look at her as a minor - as in Tswana culture - and/or his property as he had paid the bride price for her[5]. - Other sexually transmitted infections (STIs) play a contributory role as they promote the transmission of HIV. They are widespread, but frequently overlooked or not treated adequately due to lack of information, difficulties of access to health care facilities and unwillingness to seek help for fear of being badly spoken to by health care providers; these factors apply again particularly to women.

We have seen that poverty and circumstances not of the people's own making play a great role, but not the only one regarding present day risky sexual behaviour. Many engage in uncontrolled sexual activities because values have broken down, because they do not challenge prevailing attitudes about sex but think that they have to conform with them because promiscuous behaviour is the thing one must do to be recognised and kept in esteem by one's peers. This not seldom applies in particular to those who are socially better off. In other instances the dominant traditional culture itself justifies practices that promote the spread of HIV. For instance, in Swaziland men still maintain that culture gives a man the right to have sex with his wife's younger sister without her consent. Poligamy is culturally accepted and legal; this leads to older men starting relationships with school girls with the tacit approval of the girl's father provided men offer services to the latter or pay the bride price.[6] But it would not be fair to single out the Swazis. We all know that in cultures where poligamy was previously the normal practice, it is rather commonly accepted that married men have girlfriends or mistresses. In the age of AIDS these married men prefer the very young girls because they consider them not to be HIV infected and therefore safe - a wrong perception as studies have shown.

So much about the background to the rapid and unchecked spread of HIV; what about the endstage of HIV infection - AIDS?

AIDS and its effects on the people

In Zambia, Zimbabwe and Malawi - the countries where HIV first spread - AIDS has become part of daily life. There is hardly a family who has not experienced a death through AIDS. Funerals of young people are common events in any community to an extent that people are no longer able to attend them as traditional rules prescribe. AIDS figures obtained from notifications are far below reality; one therefore uses estimates to get some rough picture of what prevails. In Zambia it has been estimated that about 80 - 100 000 will die during 1997, mostly persons in the age group 20 to 44.[7] The same age group shows an excess mortality in Zimbabwe where reportedly about 500 persons die of AIDS every week.[8] Funerals of young people are now also happening more frequently in certain areas in South Africa, in particular in KZN. AIDS is still not perceived as a reality by those who are not professionally involved in it. This is due to the fact that the number of people dying from AIDS is still less but mainly because the diagnosis AIDS is seldom disclosed. For reasons of confidentiality, tuberculosis, pneumonia etc. are named as responsible for illness and death; although this is not really incorrect as these are the opportunistic infections resulting from the HIV effected break-down of the immune system but hides the real cause of morbidity and mortality. The number of AIDS deaths in South Africa is likely to increase to 200 000 in the year 2000 as predicted by Doyle.[9] Furthermore the already rampant incidence of tuberculosis in RSA, in particular in the Western Cape, will be aggravated by simultaneous infection with HIV.

A few very recently published figures demonstrate some of the demographic impact of AIDS, i.e. the effects on the overall mortality and the mortality within specific age groups calculated for the year 2010:[10] The so-called Crude death Rate, i.e. the number of annual deaths out of a total of 1000 people is estimated to be sixfold higher in Zimbabwe, fourfold in Botswana, threefold in Zambia as a result of deaths due to AIDS. This means

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[5] D.S. Macdonald, Notes on the socio-economic and cultural factors influencing the transmission of HIV in Botswana, Soc. Sci. Med. Vol. 42, No 9, pp. 1325-1333

[6] Personal communicationn

[7] Risk analysis, AIDS Analysis Africa Vol 7 (1), 8-11

[8] International Programme Center, Population Division US Bureau of the Census, HIV Surveillance Data Base, June 1996

[9] Doyle PR. The impact of AIDS on the SA population (see footnote 4)

[10] K.A. Stanecki, P.O. Way, The demographic impacts of HIV/AIDS - Perspectives from the world population profile: 1996, International Programs Center Population Division U.S. Bureau of the Census Washington, D.C. 20233, IPC Staff Papere No 86 March 1997

for instance that in Zimbabwe 29 out of every 1000 people will die in a year as a result of AIDS instead of 5 out of every 1000 without AIDS and so on.
The so-called infant mortality, i.e. the number of infants under one year of age out of 1000 infants born alive who die within one year, is for instance likely to more than double in Botswana as a result of AIDS and the number of deaths among children between the ages of 1 and 4 years is likely to more than treble as a result of AIDS.

From these figures let us return to what they mean in reality: AIDS means enormous physical, psychological and spiritual suffering for the infected persons and far reaching consequences for families and communities. Poverty and underdevelopment, which have been identified as co-factors of the rapid spread of the infection in developing countries and among marginalised people anywhere in the world, are worsening as a result of AIDS. Young adults get sick and die of AIDS; they are indispensable in their double role as members of the workforce on the one hand and carers of children and old people on the other. Their ability to work progressively weakens; the result is loss of productivity and income. At the same time expenses mount for treatment - the more so as the patient tries to seek medical help at many places; the nursing needs of the patient are a burden particularly for the women who are the traditional care givers. Frequently the last economic reserves of the family are used up and credits or rents can no longer be paid.

Women are exposed to further economic and social deprivation through the death of their husbands; not seldom a widow is chased away by her husband's family who blames her for his illness. The chances for selfdetermined behaviour are likely to decrease further. Children are unable to go to school because they have to nurse their sick parents at home or because expenses in connection with schooling cannot more be paid. They have to watch their parents suffer and die. In South Africa small babies are being abandoned by their mothers because they are infected or suspected to be infected. Orphans may be forced to look after themselves or to risk being misused as cheap labourers by those who take them into their families. Not seldom they end up in the streets. Old women and men, instead of getting care and support from their sons and daugthers, have to take responsibility for a number of grandchildren. As a consequence the chances for qualified education and a promising future of these children and adolescents are very bleak, their later integration as useful members of the society are threatened. Thus, increased poverty and underdevelopment of the next generation are already pre-programmed. Many calculations have been made, but nobody can predict with any certainty the number of orphans to be reckoned with in each country. In Zambia 530 - 600 000 orphans are expected by the year 2000. Who can measure the physical suffering and psycho-social deprivation of these children?

A fair number of young and middle-aged well educated and experienced professionals are among the affected; their illness and death mean a heavy loss for the economy and for development, for the educational sector and all other public institutions and structures. In the agricultural sector the lack of productive workers resulting from HIV/AIDS is likely to lead to a diminished cultivation of land, to decreased production of basic food crops as well as of cash crops. A growing number of patients and deaths jeopardize the economic and organisational capacities of a local community and exhaust its capability and readiness for empathy and solidarity. The potential for conflict, for loss of the cohesion of existing community structures and their growing decline increases. Increased morbidity and mortalitiy within the most productive age group between 20 and 45 years decrease the latter's demographic weight. This means that the care and livelihood of old people and children will depend on an ever declining number of productive adults whose lives will on average be shortened. To give an example:The life expectancy in Zambia which was 51 years in 1990 is estimated to decrease to 42 years by the year 2002, mainly because of AIDS. [11]

HIV/AIDS puts also an enormous burden on the already struggling health services. The growing number of persons suffering from active tuberculosis makes matters worse. In countries like Zimbabwe and Malawi 50 to 80% of hospital beds are occupied by HIV infected persons; similar experience is made in some hospitals in RSA. As a result the care for patients coming for treatment of other diseases deteriorates. It becomes increasingly difficult to accomodate the additional expenses necessary for the improvement of hospital hygiene, blood safety measures, counselling services and management of opportunistic infections within an already insufficient health budget. The burn-out of trained staff on the one hand and their loss as a result of HIV related sickness and death contribute to a deterioration of nursing care. Based on economic research Blomberg predicted that 34-75% of the total health expenditure in RSA would be used up for HIV/AIDS related activities by the year 2005.[12]

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[11] Fylkesnes K et al.: Zambia: the current HIV/AIDS situation and future demographic impact In: The socio-economic impact of AIDS. Lusaka: Ministry of Health, 1994.
[12] Blomberg J. et al. The economic impact of AIDS in South Africa In:AIDS in South Africa...see footnote 4, page 2)

What we have seen so far is a very grim picture of a reality which many people have not yet recognised. In spite of ongoing information campaigns in the media, a variety of educational programmes, availability of counselling services and condom distribution, the HI virus has not been stopped but continues to spread. In spite of extensive research, particularly in America, a vaccine to prevent infection with HIV has not yet been found; the enormous potential of the virus to constantly changes its genetic code, is an enormous hurdle for vaccine development. Although drugs have been developed during recent years which, in combination, can prolong the life of HIV infected persons, their long term effect is still uncertain and their enormous costs make them unaccessible for the majority of affected people.

The need for a different approach

The just discussed facts lead us to the following conclusions:

- If we really want to contain the spread of the virus and the number of new infections to decrease in Southern Africa,
- if we earnestly wish that those who are infected, ill and dying, receive appropriate care and support,
- if we are seriously concerned that families and orphans of AIDS patients are not left alone,
- if we wish to avoid that whole communities suffer enormous socio-economic consequences,

then we need to look for a different approach to HIV/AIDS and its effects.

We need a different approach

- because a medico-technical solution is not in sight,
- because behaviour change which is the only effective way to avoid the main mode of spread, sexual transmission, is hardly brought about by big informational and educational campaigns and large scale provision of condoms. - (That behaviour change is possible has been shown elsewhere).

We need a different approach

- because hospitals and medical services alone cannot cope with the many patients who are ill over long periods due to HIV related disease; they spend these periods of illness mostly at home,
- because hospices for the ill and orphanages for the children left behind cannot be the solution as they are unaffordable on any large scale, increase marginalisation and stigmatisation by taking the problem out of sight. They are also culturally not acceptable for a large part of the population.

We need a different approach

- because patients suffering from AIDS do not only need physical care but psychological support and spiritual help, and
- because the manyfold problems befalling the infected and the affected cannot be tackled solely by professionals from different disciplines and cannot be solved by the efforts of dedicated individuals only.

By saying „a different approach" I refer to community sensitization and community involvement or, with other words, community and pastoral responses. I do not want to claim that this is something new; this approach is successfully practised in many parts of Subsaharan Africa and also in a few areas of South Africa. This approach needs to be extended and to be introduced where it is not yet known or practised so that it becomes universal.

The importance of community response

The importance of community as an instrument in the encounter with HIV/AIDS has first been recognised in the context of care in countries in East- and parts of Southern Africa whose hospitals got overwhelmed by patients suffering and dying from AIDS. In the meantime one realises more and more that community response is also indispensable in regard to other aspects of HIV/AIDS, in particular in regard to prevention.

What do I mean with 'community'? This is a term used frequently and casually in all kinds of situations, sometimes when a person has problems to define clearly to whom he refers. We speak of community when we mean people living in the same locality, in a village, a town or part of a town, in a rural neighbourhood, when we refer to people with the same culture, language, tradition, history, or to people who share the same profession or trade or whatever other bond. And there are the people whose common bond is their faith, their religion. It is the Christian community to which I wish to refer mainly in the context of this conference: to the Christian community as a whole, to members of different Churches and denominations, to small and bigger Christian communities found in dioceses and parishes, in Christian associations and societies - big or small communities, well organised ones or others without a structure.

Why are Christian communities called to respond to HIV/AIDS? Why is their a need for a pastoral response?

- Because Christ asks us to follow him in all what he has done. He commits us to solidarity with the poor, the sick and the rejected, he forbids us to practise discrimination and to exclude people from our lives for whatever reason.

- As Christians we are to strive towards deliverance and have to stand up for those who suffer injustice, poverty and neglect.
- As Christians we are called to be a healing community in the midst of pain and suffering, we are called to love those who are hurt, we are called to serve the sick and all those in need.
- As Christians we are challenged to be an easterly community which brings hope and reconciliation to those who face death.

My actual theme is community and pastoral responses. I do not think that we could or should make a distinction between the two. Pastoral care is an integral part of healing in the widest sense, is part of holistic care. It is not restricted to persons officially entrusted with pastoral duties but is a task delegated to all members of the Christian community, clergy and laity alike. Each one is called to bring in his and her special gifts and talents.

Overcoming denial and stigmatisation

First and foremost Christian communities must break down the wall of denial, prejudice, discrimination and stigmatisation which has been built up around HIV/AIDS all over the world and which still prevails in parts of Southern Africa but is predominant in South Africa itself. The presence of HIV infected people is denied because it touches on social taboos like sexual behaviour, incurable illness, suffering and death, particularly suffering and death of young people. Infected persons are discriminated against because people want to believe that HIV affects only the others, the outsiders, the sexworkers, those who lead promiscuous and sinful lives and that these 'guilty' people have only to blame themselves for what is happening to them; some go so far as to say that their suffering is punishment from God. This attitude compels infected persons to try their utmost to hide their infection and to use different labels for their illness in order not to become ostrazised. Strictest confidentiality, actually secrecy, are requested; not even closest family members are to know. This secrecy and silence seem necessary as long as stigmatisation, discrimination and blame are such strong and widespread forces - but this secrecy and silence perpetuate the vicious circle of denial of the problem and of non-acceptance of the affected. Both are counter-productive to any efforts towards HIV prevention and lead to complete isolation of the infected person as somebody reported in 1995 from Durban: „...what I've found is that persons with HIV here in Durban who have no work, and of course more than 50% of people won't have jobs here, will just stay locked in their rooms and not go out, not even for food. They are frightened to tell anyone about their HIV because of the stigma. And they have been advised never to tell anyone by their counsellors. And that adds to their fear, and they go downhill very rapidly. We see these people every day. They are socially dead, prematurely dead."[13]

I do not want to be misunderstood that I am against confidentiality, against protection of individual privacy but I wish to stress the dire need for more openness, for the acceptance that HIV/AIDS affected people are in our midst. Christian communities must try to break this vicious cycle of blame and stigma, must become aware and make aware that nobody is „immune" against HIV, that everybody is in one or the other way in danger, that there is no room for a new form of apartheid. Only full understanding and acceptance by the community enables those among the infected who are prepared to do so, to 'come out', to stand up and disclose their infection and become active partners in preventive work. It is a worldwide experience that the participation of HIV infected persons is of benefit to educational and other activities which address HIV/AIDS issues.

Finding solutions to prevention

Becoming aware of the HIV situation in one's community, accepting this reality, stopping denial and prejudice are the beginning and a prerequisite to any further action. Communities should try to find out the main factors which contribute to the spread of HIV in their midst. Identification of specific circumstances may lead to preventive measures only a community can take. Individuals - unless they are very strong personalities - have difficulty not to act according to societal norms. If such norms are rooted in age old traditions, beliefs and rituals, then the individual feels powerless against them. Only communities which recognise the negative effects of certain traditional behaviours are capable to change them through interaction and common consent. Just a few examples from other countries what community action can achieve: In some ethnic groups a widow has to be cleansed through sexual intercourse with a brother or other male relative of her deceased husband; in others she gets married to her brother-in-law in order that she and her children be provided for. If the husband died of AIDS she is likely to be infected already and now spreads the virus into the extended family. In other ethnic groups sexual intercourse with an adult man is part of the initiation ceremony for young girls - what an ominous introduction to early suffering and death this may be! Reports from Zambia and other countries reveal

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[13] Cited by Gill Seidel: Confidentiality and HIV status in Kwazulu-Natal, South Africa: implications, resistances and challenges, Health Policy and Planning, 11(4): 421

that communities have assessed the effects of such traditional norms in view of AIDS and have subsequently abandoned them.

Much more important and universally applicable than these just mentioned specific issues is the need for proper guidance of young people in regard to their sexuality and how to deal with it responsibly. Parental guidance is lacking; parents do not know how to speak about it to their children. As a 14 year old girl remarked when she addressed the 1995 International Conference on AIDS in Africa in Campala: „In my country, Botswana, there is a serious problem of communication between parents and their children. This is a cry from our hearts. Parents - talk to us. Without your communication, guidance, dialogue we are a lost generation, come to our aid!"[14] Old traditions and rituals to prepare young people for adult life are no longer practised at all or not in the proper manner. In an endeavour to become part of modern society, to be like their peers, most young people have long dropped old norms. A 17 year old from Uganda stated: „My friends tell me to drink and have sex if I want to be cool. I know that life is not all about being cool - but what can I do?"[15] It is futile to expect that simple statements and threats about the dangers of HIV have a real and lasting influence on behaviour.

What an opportunity this is for Christian communities to step in and to fill this void and to engage in activities which lead to changes in patterns of behaviour and attitudes. Young people need guidance not just about the prevention of HIV infection but about the meaning and expression of sexuality within a life style which respects values and has perspective. They need to be accompanied through stages of growth and to learn skills how to solve problems and how to make decisions, how to build self-esteem, to develop a sense of responsibility and the courage to withstand pressure. It is necessary to encourage and to enable adults to do justice to their educational role towards their children. The adults have also to learn in participatory educational settings how to speak with their spouses about their own sexual relationships in order to improve them, in order to be exemplary to the next generation. Members of youth groups have to be motivated and assisted to act as multiplicators for their peers, particularly for those outside their own circle, for those without bonds to family, school or community life.

In this context I wish to mention a local example of community action regarding education of young and not so young people, the programme of Umanyano Lwezizukulwana in nearby Gugulethu. This so-called multigenerational women's group has recognised the vulnerability of young women to which the breakdown in communication between mothers and their daugthers contribute. In response to questions the majority of women had indicated that they had heard of AIDS but did not believe that it was a serious problem nor did they feel personally at risk. Sex for them was doing whatever the partner wanted to do; talking about sex with the partner was a matter not thought of. In consequence they have seen an urgent need for bridge-building and interaction between the older and younger generations. The organisation trains peer educators in its different branches and wants to revive aspects of Xhosa culture such as story-telling as one of the methods used. The improvement of relations between generations is seen as perhaps the most important step to help young women and girls examine their values, lifestyles and behaviours.

Educational activities alone are not enough if lack of possibilities for leisure and recreation lead to extreme boredom of the youth and young adults; this situation is aggravated by a high rate of unemployment. It does not help to complain about facilities and activities which promote risky behaviour unless something is done about it. Through participatory planning and action by all members of communities innovative ideas can be generated and implemented. Community action is also called where human rights are violated, where, for instance people are denied access to work or to leisure activities on account of their HIV infection, where discrimination in whatever form is practised.

Single communities are limited in their capability to bring about changes in the socio-economic conditions which promote the spread of HIV. Nevertheless, they should try in as far as this is possible, to assist development and upliftment. Any action which brings about real development of persons, and, in particular, of women is also an action to assist prevention of HIV spread. It is a particular duty of the Christian community as a whole to again and again speak out against injustices in society which are responsible for poverty, underdevelopment, the separation of families and gender inequality and unmask them as decisive factors for the rapid spread of HIV/AIDS.

The community as carers for HIV infected persons and AIDS patients

As already mentioned care programmes initiated community involvement in HIV/AIDS work. The so-called Home Based Care Programmes (HBCP) were first started by hospital staff who were deeply concerned about the

[14] AIDS and young people, Panos AIDS Briefing, No 4, July 1996
[15] AIDS and young people, Panos AIDS Briefing, No 4, July 1996

many AIDS patients who were discharged from hospital and living under miserable conditions at home. By sending a team of professionals from the hospital into the community one hoped to provide some assistance. It was soon realised that these teams could not cope with the enormity of the task. It was found that it was not enough to show members of the patient's family what to do but that it was necessary to involve other community members as volunteers. The Chikankata Seventh Day Adventist Hospital in Zambia was one of the first which became known for this service and was imitated by others. There are now many hospitals in Southern African countries which run such services in the areas from where their patients come. These so-called hospital-based HBCPs are costly, their range is limited on account of distances and transport costs and the time limit imposed on the individual visit; they also serve mainly those patients who had at one or the other time been admitted at a particular hospital. They are a form of outreach service in which the community is not the initiator and the main role player but in which community members can play a part as helpers.

Before giving some details on Community Based Home Care (CBHC), the question needs to be answered: Why do we talk about HBC in the context of AIDS as if it was something new? Is care of an ill person by family members not the most natural thing practised all over the world all the time and part of African culture? It certainly is; but specific issues arise when the person to be looked after at home is HIV infected or dying of AIDS. These problems are experienced worldwide as a result of

- ignorance, anxiety, denial, stigmatisation and rejection,
- the fear of becoming infected by providing nursing care,
- the fear, that confidentiality may be broken,
- the despair and despondency as a result of the knowledge that the disease is fatal,
- the feeling of incompetence and the perception of insufficiency of home service in view of a serious disease, and
- the feeling of powerlessness to cope with the situation.

In developing countries and resource poor regions additional factors make home based care particularly problematic:

- the socio-economic conditions of poverty and the lack of a well functioning public social network make appropriate care at home appear unrealistic;
- the predominantly heterosexual transmission frequently leads to illness of husband and wife at more or less the same time; the main burden of nursing is falling on the wife as the traditional care provider; she is frequently sick herself;
- the usual support by the extended family may not be forthcoming due to fear and rejection and/or as a result of the AIDS related decrease in the number of young and middle-aged adults in a family, or, because there is no extended family available as a result of urbanization.
- the effects of illness and bereavement are likely to destroy the already weak socio-economic position in a manner that even the bare necessities of life can no longer be procured.

These just mentioned factors explain the need for support by a group larger than the immediate or the extended family. This is the reason why community members must help, why their help must be organised and why often financial assistance from an outside source is necessary, at least temporarily to get a HBC service started. What are the needs a CBHC Service must address:

There are the needs of the HIV infected/AIDS patient who wants

- to be accepted by family, friends, community;
- to be helped in his struggle with fear and anger, feelings of guilt and low self-esteem, despair and loneliness;
- to know how to avoid infecting others,
- to have confidentiality maintained as far as possible.
- Basic requirements like food, water, shelter must be met (patients name frequently poverty as their main complaint)
- Relief is needed in respect of the many symptoms of disease like pain, diarrhoea, nausea, skin conditions etc. and access to medical care for specific problems.
- Plans have to be made for the future of the family, in particular the children left behind; this may mean attention to legal issues and the writing of a testament.
- And: the patient wishes to die in dignity and in peace with his creator and those dearest to him.

There are the needs of the family members:

- They need to know about the disease, how it is and how it is not transmitted.
- They must be helped to accept that their father, mother, brother, sister, husband, wife, son or daughter is HIV infected.
- They need to be enabled to function as the primary care givers; they must learn how to render basic nursing care; items like soap and desinfectant solution and perhaps linen and blankets must be available.

- They need continuous support in order to face the practical problems of care and to deal with feelings related to death and bereavement.
- And: they must be able to survive during the illness and after the death of the breadwinner or the mother of the family.

From what has just been said it becomes obvious that actual medical care forms only a small part of the felt needs and that high professional input is not asked for. The main purpose of a HBC service is:

- to maintain and improve the traditional coping mechanisms, i.e. to strengthen and qualify mutual help within extended families and neighbourhoods and to include all in need into this network;
- to assist the affected and their families in whatever manner necessary and feasible;
- to implement measures to avoid breakdown of community structure and cohesion, and
- to promote prevention; caring for the sick without fear influences people's behaviour and attitude much more than giving educational talks.

CBHC has to go beyond the alleviation of suffering of individuals which was its initial aim. Communities must not only be included as targets and helpers of HBC programmes but become the active initiators, planners, organisers and implementers of such services. HBC must mean holistic care in and by the community within a continuum of care in co-operation with health institutions and social services where such exist. Responsible family members and particularly the patient must be included as active participants in all decisions which affect the care and the circumstances of daily living and the future of the family. Care for the family should continue after the death of the breadwinner or the mother of the family when the widow does not know how to cope or when orphans are left stranded on their own or are not looked well after by the relatives or a family who took them in. Confidentiality in the context of such a programme means confining the knowledge of a patient's HIV/AIDS status to as small a number as possible of specified people, with the patient's consent (so-called shared confidentiality). Studies in different countries have shown that CBHC programmes are more cost-effective and have more potential for sustainability than the hospital based programmes.

Let us look at a few examples of CBHC programmes in countries of Southern Africa:

In Malawi a Home Based Care Programme was started in 1992 by the Episcopal Conference of Malawi as a pilot project but has gradually been integrated into the communitiy. So-called Home Based Care Providers who are part of the community but are employed fulltime are entrusted with the double role of providing services to the patients on the one hand and to be a catalyst for community involvement on the other. Their professional background is that of staff nurse, teacher, clerk or a similar occupation; after being trained each one becomes responsible for the service in the area of two parishes, mostly rural ones, which they cover on a small motorcycle or on foot. They assess the needs of the patients, teach the family members basic nursing skills, counsel the patient and the family, pray with them and also provide some basic medicines for symptom relief. An official link with a health institution does not exist but cooperation is maintained. Most of the actual assistance to patients and families comes from volunteers, mostly women, but also men of all ages who are themselves subsistence farmers or hawkers and who - out of a sense of Christian commitment - devote a few hours or a day every week to AIDS patients as well as to a few other chronically sick, home-bound persons. The volunteers - there are 20 to 50 or more working under one home based care provider - assist with tasks like fetching water, washing and cleaning, cooking a meal and they give company. They refer sick persons or others who need counselling to the home based care provider and/or the clergy. Educational activities in schools and with parish groups are also tasks performed by the care providers and the volunteers. Groups in the commuity - again it is mostly women or widows respectively - are encouraged and assisted to develop income generating activities like rearing of chickens, baking, gardening in order to gain some income for the support of families who care for orphans. Financial support is obtained mostly from an overseas organisation for the modest salaries of the home based care providers, their transport and expenditure for training, some limited material assistance to patients and seed money for income generating activities. Spiritual support from the clergy has been identified as an asset for the programme. The volunteers work best at places where arrangements are made for them to have some small incentive like badges or T-shirts for identification and not only educational but also some small social meetings.

An interesting programme in an urban area where the initiative originates in the community is the integrated AIDS Programme in the Copperbelt Province of Zambia whose declared goal it is to address the epidemic in the widest context for the most vulnerable in society. The objectives are:

- community initiated home care for chronically ill patients, in particular those with symptomatic HIV infection, and their families in 21 shanty compounds in the Province
- care for children affected by AIDS, i.e. orphans and children of families where the parents are unable to care due to HIV infection;
- increase in awareness on HIV/AIDS of the population, and

- to enable the most vulnerable group in the compounds affected by AIDS, i.e. women left behind without any source of income, to earn a small income.

The AIDS Department of the Diocese of Ndola plays a role as coordinating body for the local home based care and prevention activities and for the international donor community of six NGOs. Criteria for assistance are:
- the initiative has to come from community organisations, mostly Christian ones, which have recognised the problem and committed themselves to do something about it;
- the programme should be accessible and acceptable to every person in the community;
- the programme should be in a compound where living conditions are below average.

Church or other community groups approach the diocese for assistance and are then sensitized in order to know what is possible and what not in such a programme to avoid that they have too high expectations. The groups select the volunteers who should be people with enough time and energy to do the work and who preferably come from different denominations and different areas of the compound in order to guarantee proper cover. Trained volunteers identify patients who seem to be suitable candidates for the programme. These patients are then assessed by a nurse together with the volunteer and an action plan is made by them in consultation with the patient and the family. The care is then supervised and rendered respectively by the volunteer who may call on the nurse when the need arises. Material needs of patients and families find relief as far as possible through help from the diocese. In 1995 it was reported that the programme cared for about 5 500 patients; a total of 33 000 to 40 000 family members were also perceived as beneficiaries; a total of 500 persons volunteered for the service. This home care programme is part of a comprehensive AIDS programme which assists orphans, runs special TOT courses for teachers as well as for workers of different companies and establishes multi-functional centres, where a.o. income generating activities take place and where 'drop-in-facilities' exist.

The Family Health Trust in Zambia was established as a NGO in 1987 with the aim to respond to the AIDS epidemic in the country. Among other projects the Children in Distress Project (CINDI) provides care and support for orphans of age 20 and below. The trust works through independent community based groups called branches; a coordinator and two professional social workers are stationed in Lusaka. The members of the branches, called care takers, register orphans and identify those of particular concern. The latter are visited regularly to receive emotional support and as far as necessary and possible material assistance in the form of food, help with school expenses and clothing. The social workers are called by the caretakers when special problems arise. Most branches generate funds through membership fees and through income-generating projects; some outside assistance has also been received. Over 1600 orphaned children had been identified in nine branches by 1994, 1300 in Lusaka alone. Although CINDI is the largest effort to assist orphans in Lusaka it is felt that it reaches only a fraction of the children in need as it is estimated that around 40 000 children (i.e.8% of all minors) have lost one or both parents. [16]

Not only rather large community organisations with employed staff can do effective work. As an example of a small group I want to mention Kwasha Mukwenu, also in Lusaka, a women's club whose name means „assist your neighbour" and which was initiated by a woman teacher in the community who saw the obstacles her students face and decided to do something about it; she is the secretary of the club. 420 children with diverse backgrounds who lost one or both parents had been identified until 1994. Each club member maintains contact with 3 or 4 families, visits them to provide emotional support and material assistance when possible. The group tries to develop income generating activities like sowing to help meet the children's needs.[17]

Very useful is the integration of HIV/AIDS activities into other existing programmes. As an example for the latter I want to mention the Caring Network, the so-called Emmaus Project here in Cape Town. This Network was established in 1990 and has since spread to many parishes in the Cape and beyond. 'Care' is not restricted to care of the sick but means service to those in whatever need, means to go along with those in need (therefore the name Emmaus). Different communities have different needs; these are assessed by the groups of volunteers, who go through different stages of self development in order to become able to care for others. They learn different skills in training sessions with professionals. Since 1995 the need to care for AIDS patients has been increasingly realised in certain areas; relevant training has been offered and home based care of AIDS patients has since become part of what the Caring Network stands for. With exception of an office which organises training and coordinates the network, all caring activities are performed by volunteers.

These briefly sketched examples show similarities as well as differences in content and approach, they were not meant to give a complete picture but to show the scope of such service. There is not one model for all occasions, one and the same solution for every situation. Each HBC programme has to be tailormade, based on the particular circumstances, needs and resources of a community. What are essential elements for a functioning CBHC programme?

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[16] Action for children affected by AIDS - WHO/GPA/TCO/HCS/94

[17] a.a.

- Ideally the initiative should come from a community group who has become aware of the need and assessed the situation properly. If not initiated by them community members must at least accept the challenge and be committed to the task. Initiation by the community has proven to be the best guarantee that a service is maintained.
- Patients as well as families must accept the service, i.e. fear and prejudice must be overcome first; consensus must be reached how confidentiality is handled.
- The service must lead to an improvement of the quality of life of patients and families; however, the latter must not expect that a professional nursing service is provided. The service is meant to assist family members in their task of primary care givers.

  Volunteers are the backbone of the service; they must

  - be completely free from prejudice and capable to endure the stress of continuously looking after very ill and dying patients;
  - be prepared to devote time and efforts without compensation;
  - they should be part of the community and live in the vicinity of the patients to avoid much travelling which costs time and money;
  - they must be adequately trained, continuously supported and supervised;
  - training in spiritual care should be an important component;
  - the number of volunteers must be sufficient to avoid overload and early burn-out; and,
  - not to be forgotten - men must be encouraged to participate!

  Not to be neglected is the fact that

  - the volunteers need some kind of gratification, be this recognition within the community and/or some small material incentive; comradeship and a team spirit among them will also help to sustain their commitment. As the volunteers often belong to the underprivileged any attempts to improve their situation by helping them to acquire skills with which they can improve their financial situation, are beneficial also to their caring work.
- Some organisational structure is necessary for the ongoing management, control, monitoring and evaluation of the programme. It is necessary to avoid that home based care becomes home based neglect.
- Co-ordination with health services for the necessary back-up and with welfare services are vital in order that basic medicines and/or referral to medical care and provision of welfare benefits are possible.
- Networking with other concerned groups and organisations is important to avoid overlap of efforts on the one hand and gaps on the other.
- An important aspect is how to ensure that a home based care service is not concentrating on those close to it, those who have connections to the volunteers, those better known to the church, but that it reaches those most in need. Maybe priorities have to be set if the number of patients is such that limited community forces cannot cope; preference would then, for example, have to be given to those where the primary care givers are children or women who are sick themselves.
- Inclusion of chronically or terminally ill patients other than HIV infected ones in the home care programme helps where stigmatisation still prevails.
- No home based care service can exist without some funds. Obviously a larger organisation, involvement of employed professionals and transport needs cause higher expenses. A balance has to be found how to meet requirements for efficiency and quality, and, at the same time, how to keep costs low. Material assistance to enable patients and their families to survive must be seen as an indispensable part of any home based care service in resource poor areas. Procurement of funds is a difficult subject. Assistance from socio-economically better off areas is mostly necessary. This should however not automatically be interpreted as meaning a North-South assistance. A well organised and functioning HBC service is not cheap but much cheaper and more cost effective than admission to a hospital or a hospice.
- Last but not least I want to stress the importance of a good relationship between the different role players in a CBHC Service. There are the professionals familiar with the medical/nursing side of care, there are the professionals on the pastoral and social side and there are the many helpers without such background, with only limited training and their practical experience gained in the service. Sensibility and understanding are needed on both sides, readiness for communication and dialogue to sort out disagreements and to avoid discord, discontent and animosities within the team.

Not all HIV infected persons need the just described type of HBC service. There are those in the economically better off part of the society who are able to look after themselves physically and/or who can - as members of sick benefit insurance - rely on professional nursing services. They too, however, live in fear of death, suffer pain, prejudice and isolation. Christian communities should not neglect them. Visits to give company, to show empathy, to give spiritual support, to accompany the dying are equally needed by them. - The establishment and management of 'Drop-in-centres' where patients can meet, enjoy company, receive counselling, engage together in some income-generating activities and/or have a meal are another important contribution

communities can offer, mainly in urban and periurban areas; HIV infected persons must be active partners in the running of such places.

In conclusion: Communities must recognise that the presence of HIV/AIDS can no longer be denied and calls for urgent action. In particular Christian communities must perceive the challenge and participate in efforts towards prevention and care. The pervasive and paralysing feelings of panic and hopelessness must be overcome. In view of the enormousness of the problems and our limited resources we may feel rather helpless but in view of our Christian calling we have no choice but to commit ourselves according to the best of our common and individual abilities.

3

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HIV/AIDS in resource-poor settings: comprehensive care across a continuum

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Background: The scale of the HIV pandemic in many resource-poor settings (RPS) has overwhelmed the already impoverished health and social support systems.

Objective: To propose a feasible and applicable model of care which can be used at district level in RPS faced with the prospect of caring for increasing numbers of persons living with HIV and AIDS (PWA) requiring care, and to outline some of the immediate challenges and directions for research.

Methods: Using Zambia as a test case, a review of existing community and health institution-based care programmes and facilities was made, and opportunities missed in meeting the demands of PWA were identified.

Results: Many opportunities have been missed both in encouraging PWA to enter the care continuum and in strengthening existing care services. An affordable and accessible model of care at district level that is not dependent on expensive drugs or medical interventions is suggested, using Zambia as an example. The model requires changes in the structure, function and HIV/AIDS care messages that are in line with new knowledge about the disease.

Conclusion: This model of cooperation and sharing between health and social public/private and voluntary systems can be developed over time at a district level within existing resources, even as the pattern of the epidemic alters and resources become more available and better managed.

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Keywords: Persons with AIDS, continuum of care, resource-poor settings, comprehensive care services

Introduction

The expected increase in the number of people requiring care for HIV illness including AIDS is now being felt in most parts of the world [1]. An estimated 90% of world's HIV/AIDS burden is in resource-poor settings (RPS) and more than 70% of people requiring care are in sub-Saharan Africa [1].

In many RPS, the scale of the HIV pandemic has overwhelmed the already impoverished health and social support systems. Even if antiviral drugs, systemic antifungals and sophisticated antibiotics were affordable, they would not be the best health-care strategy. HIV is only one of the burdens on societies already stretched to their limits. Competing priorities such as poverty, natural disasters, ethnic and political instability and the resurgence of diseases previously considered to be under control must all be taken into account at the personal, institutional and national levels when planning for HIV/AIDS care.

The concept of comprehensive care across a continuum arises from lessons learnt from developing countries who have shared their experiences [2]. The range of care models must however be seen in the context of the countries in which they have been developed, and even within those countries no one model is a panacea.

This review will discuss a continuum of care from a local state-of-the-art perspective using Zambia as a test case. The model presented may be used in RPS faced with the prospect of caring for increasing numbers of persons living with HIV and AIDS (PWA) with limited resources. In addition, this review further outlines some of the immediate future challenges and directions for research.

The care continuum

The content of care delivered across a continuum contains a range of comprehensive services including coun-

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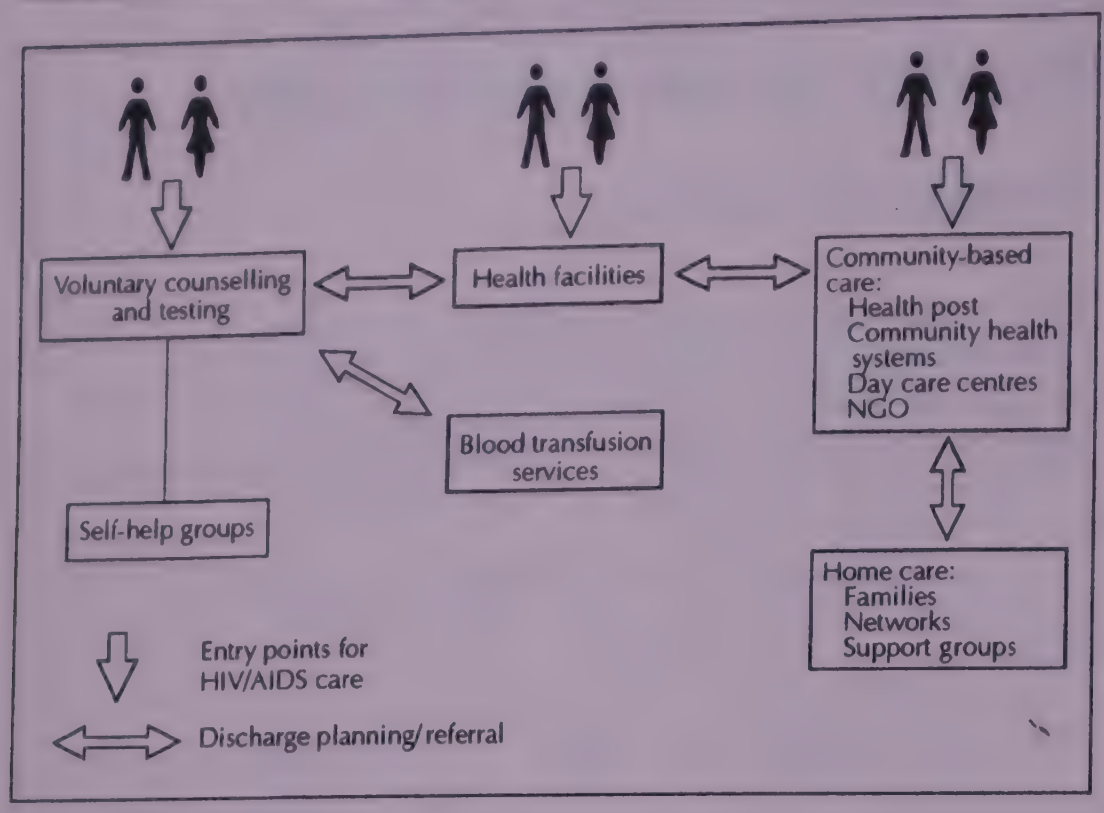

Fig. 1. The care continuum [2]. NGO, Non-governmental organizations.

selling and testing, clinical management, nursing care and community-based social support. The provision of care extends from the individual/home to the hospital, through various levels of care linked with discharge planning and referral networks and back to the individual/home. This care continuum is a dynamic structure within which the PWA must be able to move freely from one level of care to another. Thus, it should, in any given setting, be acceptable, accessible, affordable and as close to the individual and his or her needs as possible.

Early entry into the continuum of care is key to improving the quality of life, providing opportunities to plan for the future and that of the family, decreasing the socio-economic impact of AIDS, and enhancing prevention activities. In RPS, it also helps to reduce the spread of tuberculosis, maintain working capacities of PWA and strengthen health and social support systems [3].

Entry into the care continuum can occur through various channels, such as voluntary community and health institution-based counselling and testing facilities, community and hospital curative care services, national blood transfusion services and primary health-care (PHC) programmes that have integrated HIV/AIDS awareness and prevention activities. The latter include tuberculosis, sexually transmitted diseases (STD), maternal and child health, family planning and school health activities. Fig. 1 illustrates the HIV/AIDS care continuum.

Other entry points include community home-based care programmes run by non-governmental organizations (NGO), and village and town health committees. Most of these organizations in the pre-HIV/AIDS era had already been running PHC programmes to which they have now added HIV/AIDS care [4].

In many RPS, traditional healers handle a considerable number of PWA. Consequently, there has been an increasing recognition of the need to sensitize traditional healers in HIV/AIDS prevention and care issues [5,6]. In Uganda, a 4-year collaborative project on-going since 1992 and encompassing both western clinicians and traditional healers has shown they can successfully work hand in hand for the prevention and care of AIDS in Kampala [7]. Sensitized traditional healers therefore form yet another entry point for PWA into the continuum.

PWA in RPS who have announced their serostatus, have expressed their needs. These are wide-ranging and distinctly differ from those of PWA in affluent societies. Table 1 compares the needs of PWA and their families in RPS with those from affluent societies. PWA in RPS are concerned about basic needs for food, shelter and first-line treatment of ailments and opportunistic infections, access to care, social acceptance, and financial and material assistance for survivors [2].

Missed opportunities towards a practical and programmatic continuum of care

Zambia is suitable to be a test case towards a practical and programmatic continuum of care, as well as demonstrating missed opportunities in the provision of this care. Around 65% of adult medical in-patients in the country's large urban hospitals are HIV-seropositive [8]. The picture in most other RPS is not much different [1]. Antenatal HIV seroprevalence rates range from about 13% in rural areas to 34% in urban areas [9]. More that 80% of individuals in Zambia have a family member or close relative who has died of HIV. Every class in every school

Table 1. Needs of people living with HIV/AIDS and their families.

Affluent environments*	Resource-constrained environments†
Right to work	Access to primary care and empathy
Confidentiality	Financial assistance, daily needs and security of survivors
Care and access to treatment trials	Material assistance: food, soap, linen, clothes, helping hands
Bereavement counselling	
Emotional support	
Appreciation of sexual needs	

Sources: *The Programme for Appropriate Technology in Health, Australia 1992; †The AIDS Service Organization, Uganda 1994.

Table 2. Impact of HIV/AIDS on the health system.

City	Hospital	% Beds occupied by AIDS patients
Lusaka	University Teaching Hospital	65
Kinshasa	Mama Yemo Hospital	50
Kigali	Central Hospital	60
Bujumbura	Prince Regent Hospital	70
Chiang Mai	Provincial Hospital	50

Sources: Reijer [8] and van Praag [21].

includes an orphan and an even larger number of children are within families that are affected. The National AIDS/STD/Tuberculosis and Leprosy Programme estimated the number of orphans at 250 000 in 1995, with an increase to 550 000–600 000 by the year 2000 [10]. Table 2 shows the impact of HIV/AIDS on health systems in Lusaka and other selected major cities in RPS.

Opportunities towards an implementable continuum of care have been missed in two ways: in getting suspected or known PWA to enter the care continuum, and in strengthening existing care services.

Missed opportunities in relation to entry points

Community-based voluntary counselling and testing centres

Although Zambia has been training professional HIV/AIDS counsellors since 1991, the first community-based voluntary counselling and testing centres were established in 1993 in Lusaka by a local NGO called Kara Counselling. Testing at Kara Counselling, for those who can afford it, is at a subsidized rate of US$ 0.50. Through what is known as Hope House, a care service run almost entirely by PWA, Kara Counselling also provides psychosocial support, shelter and clinical care for minor ailments.

The apparent success of Kara is however marred by the obvious gap between its testing activity and other care services (Zulu Winston, personal communication, 1996). Between January and May this year, Kara tested over a 1000 'worried well' clients of whom approximately 40% were HIV-positive, whereas Hope House only handled 70 HIV-seropositive clients. Tested clients although routinely given information about Hope House are not compelled to visit it. Furthermore, the clients of Hope House need not have been tested by Kara but must show proof of HIV seropositivity.

Two other programmes also established centres in Lusaka — the Morehouse School of Medicine and Project San Francisco — in 1994 and 1995, respectively. Testing at these new centres is free because it is linked to other projects, such as an STD control study in the case of Morehouse School of Medicine and a study of discordant couples in the case of Project San Francisco. Testing within the context of the projects is used primarily as entry points to HIV prevention rather than care *per se*.

The majority of PWA in Zambia are not aware of their serostatus. Linking testing to provision of care may serve to increase the numbers of people entering the care continuum. When testing is not linked to care, opportunities are lost in getting PWA to enter the continuum. To date no other community-based voluntary counselling and testing centres have been established in towns other than Lusaka, despite the obvious need for this service.

Hospital-based voluntary counselling and testing centres

A number of government- and church-run hospitals in Zambia have initiated in-house counselling and testing facilities with strong links to care. This has been within the context of NGO or project-initiated outreach home-care programmes. At Lusaka's University Teaching Hospital (UTH) three such programmes are in existence.

The family support unit, an initiative of the Department of Paediatrics and Child Health and the Society for Women and AIDS in Zambia, uses the sick child as an entry point to family counselling, testing and home care. On the other hand, the UTH home-based care unit, an initiative of a local NGO called Family Health Trust, caters for the adult population referred to them from the wards in the hospital. The third, called the Zambart Project, a collaboration of the UTH, the University of Zambia School of Medicine and the London School of Hygiene and Tropical Medicine, has been looking at isoniazid chemoprophylaxis in HIV-seropositive adults, and both the testing and subsequent home-care has been project-linked.

Ensuring follow-up through discharge planning and referral to other levels for people entering the care continuum through either health facilities or counselling and testing facilities has been difficult, resulting in considerable attrition and loss to follow-up. The Chikankata Hospital home-based care programme, a hospital initiative, and the Ndola Diocese home-care/continuum project, a community initiative, are two of the few successes in Zambia that have developed strong discharge planning

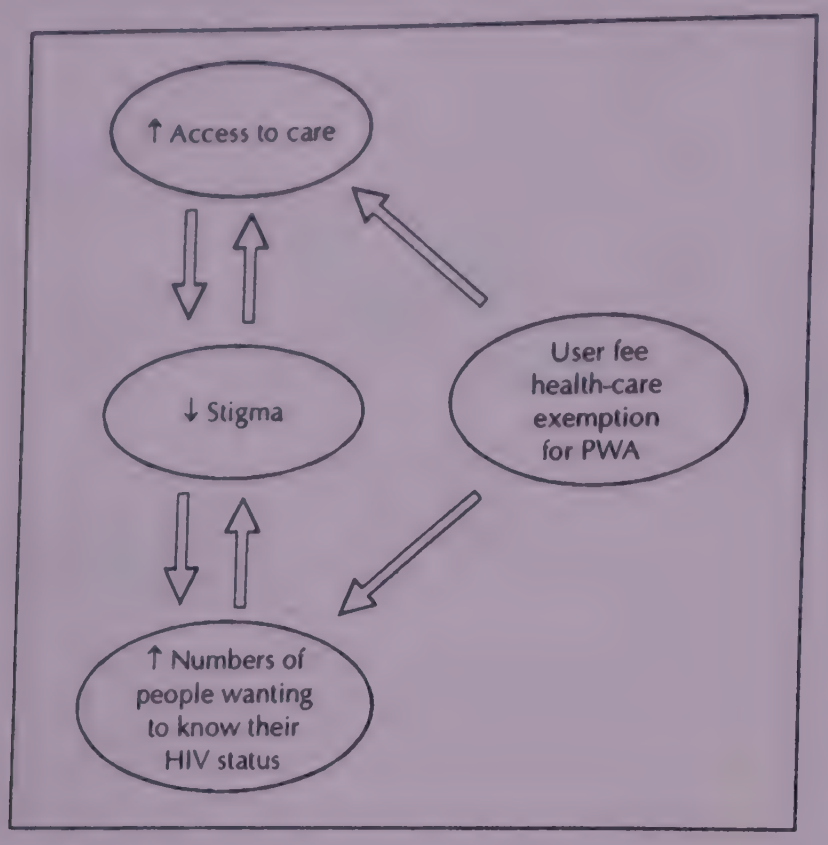

Fig. 2. User fee health-care exemption for persons living with HIV and AIDS (PWA) as a strategy for reducing stigma and increasing both access to care and wanting to know their HIV status.

and referral links. However, the successes of these care continuum models are in part attributed to the strong financial backing they receive through their churches.

Entry through primary health-care programmes

Although HIV/AIDS activities have been integrated in all PHC programmes, counselling does not always take place at the community clinic level due to the lack of widespread testing facilities. Testing, when performed, is unfortunately seen by both the client and health worker as the end of the road and not the beginning. The high mortality and morbidity rates in PWA have led to many health workers being unable to openly discuss HIV/AIDS with clients. Counselling is further compromised by shortages of staff, too many clients and simple burn out.

Missed opportunities in relation to strengthening care

User fee exemption for PWA

Zambia Health sector reforms do not address the issue of HIV/AIDS care. PWA whose serostatus is known to health workers are not exempt from paying user fees unlike patients with tuberculosis and, paradoxically, other STD. Most are unable to pay medical insurance for themselves, let alone for their families if they are the 'breadwinners'. Social welfare schemes have been put in place in Zambia but have not been easily accessible. User fee exemption for PWA might not only increase access to care but may also lead to increased numbers of people wanting to know their HIV status which would lead to a decrease in stigma (Fig. 2).

HIV remains a very stigmatized condition in many RPS and even when PWA are able to acknowledge their status, many are unable to tell anyone including their spouse about their status. Consequently, they deny themselves the opportunity to turn for support to family and friends [11].

Integration of research results into care protocols

Countries like Zambia have a rich resource of study subjects which attract many researchers. It is unfortunate that planners continue to make decisions using data generated in other countries which may or may not be relevant to the Zambia situation, although none of the reported HIV/AIDS studies performed in Zambia have evaluated this [12]. Furthermore, opportunities have been lost in carrying out controlled studies, such as which simple, cheap and effective treatment regimes work for medical problems in the Zambian context.

Results of several clinical studies performed in RPS in collaboration with scientists from affluent societies have been important. Unfortunately, results have been made use of more by the affluent societies than by the RPS where the data was generated. This has in part been due to poor dissemination of results at the local level. Furthermore, many scientists in RPS are unable to subscribe to peer review journals where most of these studies are published.

Palliative and terminal care

It therefore follows that if people know what works in each condition and at which level it is available, they could therefore know at which stage in the disease to seek or provide palliative or terminal care. When a decision is reached, palliative care should be home-based unless there is nobody to look after the person in the home or community. The current situation is that most hospitals in RPS are being used as hospices. The role of community-based hospices has not been explored in Zambia as it has in many other RPS.

Support to children and families affected by HIV/AIDS

The chronicity of HIV with no immediate prospects of available specific treatments has shaken societies, particularly those in the African region, with some exhibiting an almost fatalistic attitude towards the disease. Care across a continuum would not be complete without support to children and families affected by HIV/AIDS. This support is not only necessary when the person dies but also when he or she is still alive, so that all affected children can be encompassed and not just the orphans.

The 1994 Lusaka meeting on support to children and families affected by HIV/AIDS was attended by all countries in the region [13]. This meeting made far-reaching recommendations for countries in RPS and strongly advised against the creation of new orphanages.

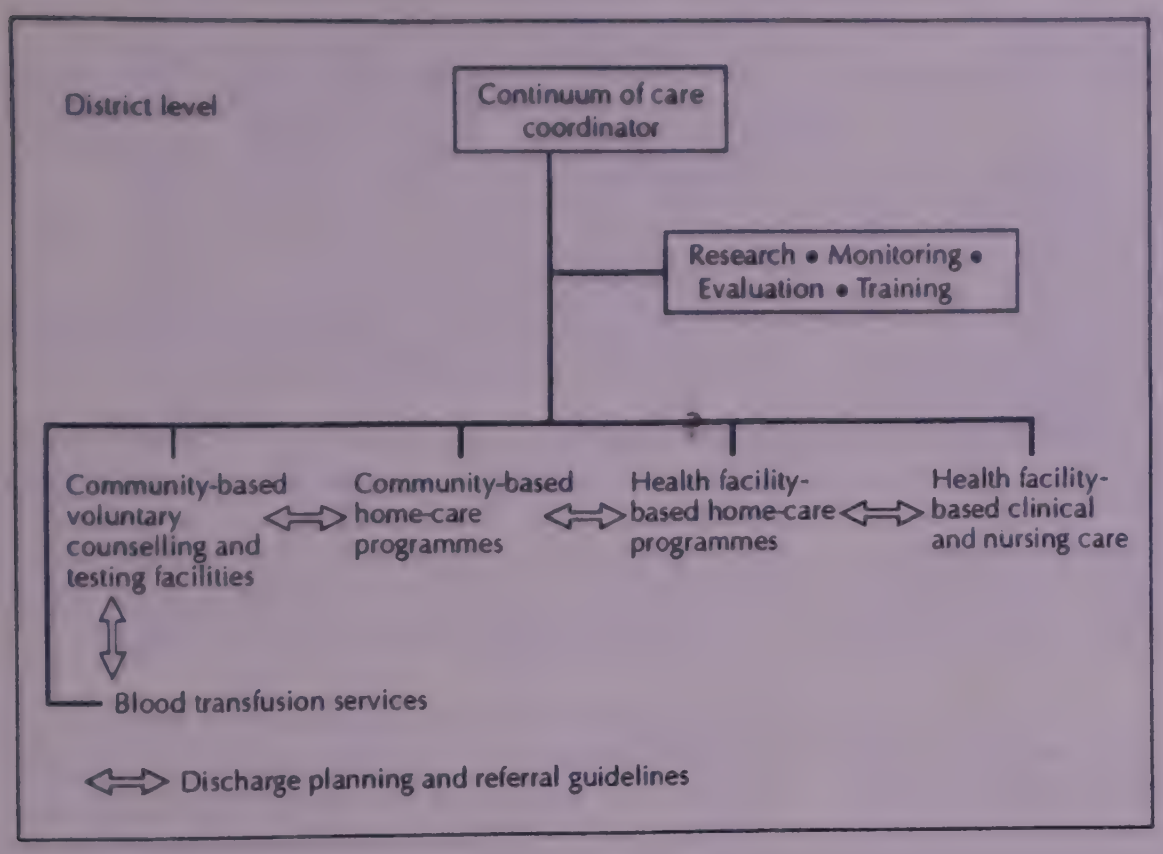
District level
Continuum of care coordinator
Research • Monitoring • Evaluation • Training
Community-based voluntary counselling and testing facilities
Community-based home-care programmes
Health facility-based home-care programmes
Health facility-based clinical and nursing care
Blood transfusion services
Discharge planning and referral guidelines

Fig. 3. The care continuum organogram.

Not too long ago, in Zambia, there was little concept of nuclear or extended families, although this has increased in recent times. The whole community was 'family', with every child being a son or daughter of the community. Had HIV/AIDS come on the scene in that era, communities would certainly have coped better than they are doing now.

The care continuum organogram

The Zambian Health Reforms emphasize decentralization of health services. The concept of a continuum of care therefore fits very well as a programme within the reforms, as illustrated by Fig. 3. Thus, at district level in the Zambia context, one imagines a continuum of care coordinator assisted by several technical committees responsible for the specific comprehensive care services within the district, including one for research, monitoring, evaluation and training. PWA would have to be represented in each of these committees and the role of health facility-based outreach care programmes would be one that excludes home visiting. It would then be left to the coordinator to ensure that all services within the district are strongly linked to each other by discharge planning and referral networks if continuity of care is to be achieved.

Immediate challenges

Although it is necessary that RPS continue to forge ahead with HIV awareness and prevention activities, it is now even more necessary for them to start focusing on care as a priority strategy in its own right. Care in RPS might be expected to be a powerful tool for consolidating prevention activities and limiting the spread of HIV.

First, RPS need to acknowledge that an effective and feasible continuum of care is attainable even within the constrained resources. Second, the issue of stigma must be seriously addressed. In RPS the continued stigma associated with HIV is one of the most critical factors in the effort to increase access to care. The fear of disclosure of serostatus is found not only at the community level but also in health institutions, where ill infected health workers would rather seek care in other health institutions than their own. Stigma is also constantly reinforced by an unlikely avenue where health messages continue to equate HIV with promiscuity.

No single model of care is a panacea, but whichever model is put in place must integrate traditional values with modern necessities. HIV/AIDS experts in RPS should revisit the many western model intervention strategies that have been put in place and seek to develop their own based on the input of local PWA, their families and communities. In this way, planning would be bottom-up rather than the usual top-down format. In RPS hard hit by the pandemic, some local medical experts have questioned the time- and money-consuming pre-HIV test counselling in high HIV prevalent populations and advocate to continue a medical culture where all diagnostic and treatment issues are in the doctors' hands [14]. At the other extreme, testing for HIV at home is something that seems imminent in some affluent societies [15]. However, this should not be expected to be free of negative psychological or social effects. There are others who argue that the side effects may even outweigh the expected benefits [15]. Sooner or later, RPS will have to work out their own policies related to this. In the meantime, more affordable

community-based voluntary counselling and testing services should be established in areas where this has not already been done.

In RPS, we need to strive to build individuals' confidence in levels of care closer to their homes, and we also need to lay the facts bare. Paediatricians and other paediatric health care workers in RPS hard hit by the pandemic have been silent on the risk of HIV transmission through breastmilk. This has been particularly the case when counselling seropositive pregnant mothers and those who have just delivered, who are suspected or known to be HIV-seropositive. Breastfeeding policies in RPS therefore need revisiting in the context of the risk of mother-to-child transmission through breastmilk. There is therefore the need to know which messages to transfer to mothers under these circumstances.

Persons in RPS have heard of the HIV treatment and vaccine advances taking place in affluent societies [16]. Strategies for reducing perinatal transmission would be particularly important in settings where relationships depend heavily on having children. Antiretroviral treatments are currently unaffordable in many RPS. Cheaper and virtually harmless antiviral strategies such as routine vitamin A supplementation for HIV-seropositive pregnant mothers may help to reduce perinatal transmission [17]. Pregnant women are more likely to be vitamin-A-deficient [18], which is increased in HIV-seropositive women [17]. Given that there is an association between vitamin A deficiency and immunosuppression, this, together with the effect of HIV on the immune system, is expected to pose an increased threat to CD4 counts [19,20].

We need to know which PWA might benefit from simple treatment regimes for the control of opportunistic infections. In RPS, the need for a comprehensive care across the continuum will still be necessary even when vaccines and cures become available.

Last but not least, HIV is rapidly becoming a potentially treatable condition in affluent societies. It is important that before it becomes just 'another tropical disease' it continues to be on the health agenda in order to ensure continuity of funds until it ceases to be a public health threat in all settings.

Research questions

Some of the priority questions that therefore need to be urgently answered in RPS are as follows:

Stigma issues

How can we effectively reduce the stigma associated with HIV at the personal, family, community and institutional levels? How can we encourage more people to acknowledge their status?

Capacity building

How can we strengthen capacities for clinical, epidemiological and public health research, and community-based approaches from the nursing, medical and paramedical sciences?

Cost–benefit analyses

What is the cost to the health system and to the patient of providing care at each level?

Clinical care

How can we effectively integrate research results into care protocols? What is the natural history of HIV in RPS when entry into a continuum of care is early? How can we effectively support the HIV/AIDS caregivers? Is there a role for community-based hospices in RPS?

In conclusion, this article argues that a continuum of care in RPS is feasible even within the constrained resources. The presented model of a continuum of care can be used at district level in RPS faced with the prospect of caring for increasing numbers of PWA with limited resources. The theme of the *XI International Conference on AIDS* 'One World, One Hope' is a challenge to everyone, but until global inequalities in life expectations are reduced, care for HIV in RPS will always be limited by competing priorities.

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MATERIAL ON HIV/AIDS

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AIDS AND INTERNATIONAL HEALTH DEPARTMENT

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December 1997

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6 Monitoring and evaluation

Awene Gavyole, Ties Boerma and Dick Schapink

- Can communities evaluate their own programmes?
- Is reduction of HIV incidence a feasible success indicator?
- What are the differences between output and impact indicators?
- Can the stigma associated with AIDS be measured?
- What are the steps in setting up a monitoring system?

Monitoring and evaluation of HIV prevention and AIDS care programmes provide a way to see if programmes are achieving what is intended. Both monitoring and evaluation need to be planned into a programme from its beginning.

Programme *monitoring* follows the progress of ongoing activities with respect to achievement of objectives; this can be done by using indicators designed for the purpose. Are the planned activities being implemented according to the objectives and schedule? What is actually happening? The aim of monitoring is to identify problems early and suggest the action necessary for improvements in the implementation of the programme.

Evaluation can be considered both a learning tool and an action-oriented management tool. It is a process intended to determine, as systematically and objectively as possible, the relevance, effectiveness and impact of activities, seen in the light of their objectives. Is the planned approach achieving the stated objectives? Who has benefitted and how much? Evaluations are done at specific points in the lifecycle of a programme; they can improve both current activities and future planning, programming and decision making (1, 2).

Monitoring and evaluation is often a weak programme component, and AIDS programmes are no exception. Recording and reporting may be irregular and incomplete because staff have not been trained. If the purpose of the data collection is not clear and feedback is never given, staff may not be motivated to complete the arduous daily task of filling in forms. Inappropriate indicators and unmeasurable objectives may have

been chosen. The role of monitoring and evaluation in the planning and implementation cycle may be obscure. Some examples of problems encountered in monitoring interventions within a truck stop project are shown in Box 1.

Box 1. Problems in project monitoring and evaluation

A fairly sophisticated monitoring and evaluation system was designed for a truck stop AIDS intervention project in Tanzania (see Chapter 8). Peer educators were supposed to collect, record and report information on truck drivers, other travellers and condom use. Two forms had to be completed on a monthly basis: one about distribution of health education materials and one to report activities. This information was gathered by project staff, who entered the data in the computer, analysed the data and gave feedback to the peer educators. Also, a diskette was sent to the national project coordination unit in Dar es Salaam with all data.

There were multiple constraints. The peer educators' reports were irregular and incomplete, and some did not understand the coding system. The field staff of the project had problems with the computers and neither used the data nor gave appropriate feedback to the peer educators. The national coordination unit received fewer diskettes than anticipated, had operational difficulties in making summaries and gave no feedback to field staff.

Evaluation of the situation made clear that the system was too complicated in relation to the inputs (training and supervision, qualified staff and computers) available to run a system with such elaborate data collection, analysis and feedback systems. Unless a major commitment can be made to monitoring and evaluation, the system needs be simple and limited in scope.

What needs to be monitored?

In planning, monitoring and evaluating programmes, baseline data on the spread of the HIV/AIDS epidemic are needed. This is a new disease, with an insidious and potentially devastating impact on health, social life and economy. We need to know how the virus spreads in the district, what the level and trends are in HIV prevalence, and what kinds of consequences need to be anticipated. However, monitoring these aspects of the epidemic appears to be beyond the resources of most districts. AIDS cases in the health facilities can be monitored, but since the incubation period of HIV is very long this does not provide up-to-date information. Estimates about its spread will therefore be necessary, based on inferences from regional or even national data.

Districts have launched (or will launch) interventions focused on reducing HIV transmission by various modes. Most important are HIV/AIDS educational activities (in schools, communities, high-transmission areas and so forth) intended to lead to behavioural change, including condom use. Other interventions include prevention of transmission

through blood transfusion and injection and sterilization practices and those related to AIDS care. All of these call for monitoring and evaluation, which in this case must be carried out at district level.

Basic steps in a monitoring and evaluation system

Monitoring and evaluation should be an integral part of an AIDS programme. The design of a monitoring and evaluation system for an AIDS programme can be seen schematically as a number of successive steps (3, 4).

1 *Baseline data:* baseline data indicate the starting point – what the situation was before the programme began. Good baseline data thus provide a foundation for a credible monitoring and evaluation system, as well as giving a basis for planning. This data may come from a review of existing data (not necessarily limited to the district itself), a baseline survey and a participatory community needs assessment, focused on AIDS knowledge and attitudes and sexual practices in the community. For example, in preparation for a monitoring system in relation to activities in schools, a survey might be conducted among school children, parents and teachers to assess knowledge, attitude, practices and risk perception in relation to sexual behaviour and STD/AIDS. Both questionnaires and qualitative methods can be used.

2 *Determine objectives:* as mentioned in Chapter 1, both overall objectives (related to the programme as a whole) and specific objectives related to activities should be considered. Objectives related to activities should be measurable; otherwise they will not provide a guide for monitoring and evaluation. Objectives should also be limited in scope, so that they can be reached within the stated time period. The overall objective of a school AIDS programme might be to increase knowledge and improve attitudes and risk perception among school children. The specific objectives of a particular activity might relate to improvement in the accuracy of their knowledge. A more ambitious objective would be to change sexual behaviour among school children. In this case, specific objectives might include a decrease in the self-reported number of sexual partners, postponement of first sexual intercourse, increased condom use, or a reduction in school-girl pregnancies.

3 *List activities and their relationship to overall strategy, and the tasks they will require:* for each of the objectives, activities to be carried out – and the strategies that will be used in doing so, as discussed in Chapter 1 – should be considered. For example, one strategy might be to focus on the use of peer educators. In setting up peer educator activities among school children, among the tasks involved will be selection, training and regular support for the peer educators.

4 *Select indicators and set targets:* for each of the objectives associated with an activity, 'indicators' (discussed further below) and targets are needed. Targets are quite literally something to aim at – what you expect to happen with respect to the activity. The

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indicators provide a way of seeing how implementation and achievement are proceeding – is the activity on the way to the target or objective? – and eventually to show the extent to which an objective has been achieved. They should be realistic and practical. For a school programme, changes in the level of knowledge of AIDS prevention among pupils, the number of trained and active peer educators, and the number of schoolgirl pregnancies per year are examples of such indicators. Numerical targets can also be set, e.g. the target might be 'our target is to see that 100% of pupils in the highest three classes of the primary school know that HIV can be transmitted by sexual intercourse', or 'one year from now, we will have one trained and active peer educator for every 20 pupils'.

5 *Collect data:* costs and resources need to be taken into account in designing a monitoring and evaluation component. Indicators that focus on programme input and output are the least expensive to monitor; if it is necessary to cover indicators of programme effects (or, even more, impact), monitoring will be far more expensive (see below). There are many ways to collect data: a small survey may be needed to assess knowledge levels of pupils; assessing a supervision system of peer educators will require continuous assessment of the number of active peer educators; and to know the number of school-girl pregnancies, a reporting system can be set up. Qualitative information is also very important. For example, a few interviews with peer educators can produce a summary of the problems they meet in their work, and suggest *why* problems are occuring – e.g. the reasons behind a high drop-out rate.

6 *Analyse data:* regardless of whether quantitative or qualitative data are involved, data analysis often takes more time than anticipated. Analysis and report writing for even a small survey or perhaps five focus group discussions may take a few weeks. However, a successful monitoring system – one that serves to improve implementation – requires results on a regular basis. Thus programmes need to be designed so that collecting, analysing and giving feedback is built into the targets and procedures, and real efforts should be made to see that this becomes routine.

7 *Take action:* as the programme develops, monitoring and evaluation will suggest areas where improvement is needed. Sometimes a set of recommendations will be immediately apparent, and can be implemented to improve programme performance. They might be included in the routine feedback after the evaluation. On the other hand, this may provide a good opportunity to discuss the problem with those concerned and get them involved in working out their own solution. This participatory approach with staff makes monitoring and evaluation a positive experience, and is often the best way to assure motivation and implementation.

Indicators

Various levels of indicators – measures that help to assess the situation – can be distinguished.

Input human resources used in carrying out an activity, such as staff labour and efforts; knowledge and skills put into the programme, e.g. administrative, medical, communications; equipment and materials such as facilities, medical supplies, gloves; condoms; and direct funding.

Output products or coverage of activities, such as number of training sessions held, number of health staff trained in counselling, number of people reached by campaigns, number of adult STD patients treated using the syndromic approach, number of HIV tests performed, and so forth. Output indicators become more meaningful if an attempt is made to estimate coverage. For instance, reporting that 75% of the 400 total health workers in the district have attended a one week training course on counselling gives more information than just mentioning that 300 health workers have been trained. Furthermore, the quality of the output needs to be taken into account, if possible.

Process Another area in which indicators are needed relates to *process* – the way the programme implements its activities in interaction with the target population and the extent of their involvement. Indicators generally require the collection of qualitative information on how activities are run, including participants' impressions on topics such as the extent of involvement of the community in a workshop, the relevance of workshop activities, the amount of resources (including time and labour) generated by the community, and/or the number of villages requesting assistance from the programme.

Effect changes in awareness, knowledge, attitudes, behaviours (or reported behaviours) related to HIV/STD risks, preventive measures, condom use, medical care and/or counselling.

Impact impact of activities on changes in the health status of a target population; for example, reduction in HIV/STD incidence and prevalence, or alleviation of the consequences of AIDS-associated morbidity and mortality at individual, family and community levels. However, in most cases it is not appropriate to choose the number of new HIV infections as an indicator of programme success, since measuring incidence is very difficult and costly. It is also not realistic to aim for a reduction in prevalence – even if programme interventions are successful and incidence decreases, it will takes a long time for HIV prevalence to decline (see Chapter 3 on Epidemiological methods).

Generally, as we move from programme inputs to impact in the list above, the measurement of indicators becomes more difficult and more costly. In some cases, a proxy indicator (that is, a related measure that is easier to obtain and can be expected to give an idea of changes in the more complicated indicator) can be used as an indirect measure of the topic of interest. For example, condom distribution and condom demand are easier to monitor than actual condom use. Prevalence or incidence of STDs that produce immediate symptoms (such as urethritis in men) can be used as a proxy for the occurrence of unprotected sexual intercourse with infected partners.

A set of ten indicators primarily intended for monitoring AIDS programmes at the national level have been developed by the Global Programme on AIDS of the World Health Organization (5, 6). One indicator refers to knowledge of preventive practices, two to condom availability, two to self-reported sexual behaviour, two to STD case management, and three to STD/HIV prevalence or incidence. These indicators need to be collected in a population-based survey or to be based on health facility data.

Who is involved in monitoring and evaluation?

At district level, the measurement of progress within an AIDS programme is the responsibility of staff involved in the implementation of the programme. This includes the district medical officer, AIDS programme coordinator, members of the district health management team, and staff of other sectors such as education and community development. As Box 1 makes clear, however, if monitoring and evaluation are to be effective, staff need to be trained and motivated. The reason for filling in forms must be clear and feedback must be given.

If external funding is obtained for AIDS-related activities, an external evaluation may be requested by the donor. Such evaluations are carried out by experts to satisfy standard requirements. Such evaluations are costly and should not be done frequently. More commonly, a small number of external evaluators is requested to work with a team of staff, community representatives and affiliated NGO members.

Participatory monitoring and evaluation in the community

Monitoring and evaluation can also be done cooperatively by the programme staff and the communities involved in programme activities (the target groups). Such efforts are called participatory monitoring and evaluation. They are planned and conducted by the programme staff and the target groups, working together (see Box 2). The process of involvement in monitoring or in an evaluation may be an eye-opener to all participants.

A participatory monitoring and/or evaluation system can be used to assess inputs, outputs and some effects of community level interventions. One of the most important aspects of such a system, however, is the opportunity it offers to use the process of monitoring and evaluation to generate and sustain a sense of ownership and commitment to the programme in the community. This can increase understanding between the community and the staff, and helps to ensure that the recommendations resulting from the evaluation will be implemented afterwards. With a minimal level of external facilitation, activities are planned by the target group, monitoring and evaluation questions are chosen with the target group, data are collected and analysed by the community, and recommendations for planning and implementation are drawn up by the community. However, such endeavours are not automatically problem-free. An example of a process-oriented monitoring system and the difficulties encountered during its implementation is presented in Box 3.

Box 2. A participatory evaluation with female bar workers

A participatory evaluation of a mobile STD clinic for bar workers was carried out in a peri-urban area of Mwanza, Tanzania. In addition to providing information about the mobile STD clinic, the evaluation had a process goal: to strengthen the sense of ownership of the programme by the target group, the female bar workers. A team including two project staff and four peer educators (representing the bar workers) was selected. They developed two questionnaires: one covered bar workers' views of the mobile clinic and the use of condoms. The other was related to the sexual practices of the bar workers, and was intended to assess the appropriateness of the interventions. The first questionnaire was developed by the project, the second by the six-member evaluation team.

In total, 47 bar workers were interviewed by their peers. Every second day, project staff and peer educators met to discuss problems and analyse the answers given by the respondents. The field work took one week. The final analysis was done by the facilitators, and included an analysis of the records of the mobile clinic. Conclusions were discussed with the full evaluation team, and subsequently with the whole team of peer educators (10). The information collected was used to develop new messages for health education and to improve utilization of the STD clinic.

One of the most interesting evaluation findings concerned sexual practices. For example, while it is generally difficult to obtain information on anal or oral intercourse, it appeared that the bar workers were much more open about these issues during interviews with their peers than with outsiders. This led to the development of new health education messages for bar workers and their sexual partners. In addition, the data on attitudes towards the mobile clinic, its staff and services, were sufficient to allow planning for changes in the operation of the mobile clinic.

What can be done at district level?

There are apt to be existing data sources districts can put to use; also, low-cost methods can be employed to gather data that can be used to monitor the input, output and effects of interventions. These three levels offer the most practical and effective indicators for use by districts. Some examples follow.

Input

- amount of resources received from central or regional governmental levels for AIDS control or STD control activities per year;
- amount of resources generated locally for AIDS and STD control activities;
- number of trained supervisors; availability of checklists, vehicles and field allowances;
- number of staff committed to HIV prevention and AIDS care activities;

Box 3. Participatory monitoring system

Igombe is a bustling fishing village along the southern shores of Lake Victoria in Mwanza District, Tanzania. A group of young unemployed women were trained to be peer educators as part of a broad community HIV/STD education programme. To develop monitoring indicators that could be used by the peer educators and by the programme, a three-day workshop was held with seven peer educators and two facilitators. The first half of the workshop was used to explain the goals of monitoring and to discuss behavioural change. The group then developed five indicators: observed sexual behavioural change (decreases in rate of partner change of peers), friends and relatives; self-reported behavioural change; demand for condoms; prevalence of STDs (discharge, ulcers); changes in number of young women in stable relationships. Unemployment, poverty, alcohol abuse and rape were also considered important contributing factors to the spread of AIDS, but were not chosen as indicators. The peer educators agreed to have monthly meetings to discuss their work; project staff met once every three months with the peer educators.

Six months later a brief evaluation was carried out. One peer educator had moved and one was ill with AIDS. Among the five remaining women three had been active and were able to report that they themselves had changed to a single partner, and several other women in the target group had changed as well. Notably, they mentioned that hasty sex outside bars was less common now. The other two peer educators said they too had changed but the others did not agree. Monitoring of activities was weak and records were not kept well. The peer educators said they needed more training and support to keep written records of their activities. This evaluation highlights the specific difficulties that are encountered in attempting to set up a participatory monitoring and evaluation system with groups such as young women involved in commercial sex. Their educational levels are generally low and their lives are very busy, filled with attempts to solve their own and sometimes their family's (parents, siblings, children) problems. In this context, peer educators expected the project to make the largest contribution to the monitoring of activities, rather than doing this themselves. Perhaps in these circumstances it is more feasible to aim at maximum community participation at the stage of indicator development, while the project or district staff have a more prominent role during data collection and analysis, including more frequent supervisory visits.

- number of times AIDS has been on district meeting agendas (e.g. of the district health management team or district PHC committee);
- number of condoms received in the district per calendar year.

Output

- number of training sessions held; number and type of participants; types of sessions on e.g. HIV prevention education, counselling, coping with AIDS;
- number of campaigns held and number of people reached by the campaigns;

- number of supervisory visits/trips made to health facilities;
- number of condoms distributed to bars and guesthouses, and to health facilities;
- number and per cent of establishments with condoms available throughout the year;
- per cent of schools with AIDS education programmes;
- per cent of villages with AIDS action committees;
- number of trained and active counsellors in the district;
- number of people counselled on HIV status;
- number of HIV tests done;
- per cent of clinics using syndromic approach to treat STDs;
- per cent of clinics with safe injection and sterilization practices;
- per cent of clinics and maternities with adequate supply of gloves;
- number of blood transfusions given and per cent screened for HIV, syphilis and hepatitis B.

Process

- amount of resources committed to the programme by district authorities;
- number of communities actively participating in and contributing to the programme.

Effect

- per cent of adults (15-49) knowing sexual transmission route of AIDS;
- per cent of adults knowing that a healthy person can carry HIV for at least five years;
- per cent of adults who say they have changed their sexual behaviour since they have heard of AIDS (e.g. have one sexual partner now, or fewer sexual partners nowadays);
- per cent of adults who consider condoms as an acceptable method of STD/HIV prevention.

The best indicators of programme effects would be changes in sexual behaviour – such as a decrease in the number of partners and increased use of condoms in high-risk encounters. Unfortunately, people's reporting of their own sexual behaviour is already subject to many biases; it is difficult to find out about the actual behaviour. People tend to report that they have changed, perhaps because they would like to change or because they think this is what the interviewer wants to hear (Box 4). In particular, if the interventions being implemented by the programme are sending out messages about the desirability of behavioural change, the answers to such questions may even become more remote from true behaviour.

Impact

- number of schoolgirl pregnancies;
- per cent of adults reporting an STD (e.g. genital ulcer or genital discharge) in the past two years;
- number of STD cases seen at health clinics.

Occasionally it will also be possible to assess impact, but this is less frequent.

A decrease in the number of school-girl pregnancies is an indicator of impact of the programme for which data may be relatively easy to get. Here too, though, a concerted

effort will be needed to obtain complete and accurate data. Many girls may resort to abortion to terminate their pregnancies in an early stage; these may easily be missed in the statistics.

Both self-reported data on STDs and the number of STD cases seen at health facilities may rise as an HIV/STD programme begins, because of increased awareness of STDs and the need to go in for treatment. Such data should therefore be interpreted with caution.

Box 4. Behavioural change: real or reporting bias?

In a survey of four fishing villages in northwest Tanzania, 85% of adults aged 15–44 years reported they had changed their sexual behaviour since they heard about AIDS (7). Most said they had reduced the number of their sexual partners, and some said they were now using condoms. This was remarkable, since no interventions had been launched in the villages. Also, the prevalence of STDs was very high in these fishing villages. For instance, 20% reported having had a genital ulcer in the past year and 15% showed serological evidence of active syphilis. Other qualitative data from the same villages also indicated that changes had not taken place, or if at all, only on a very modest scale. The most likely explanation for the discrepancy is that people over-reported changes in their own sexual behaviour: perhaps change is now considered desirable by adult men and women, but few have been able to do this. Moreover, survey respondents often tend to report what they think interviewers would like to hear.

Attitudes to persons with HIV/AIDS are important. As the epidemic becomes more evident to the general population – because friends, family and peers are dying – attitudes may change over time. A less negative attitude and decrease in the stigma associated with AIDS could make behavioural change easier (see also Chapter 18). Although little experience has been gathered in measuring stigma, questions can be included in surveys to attempt to measure attitudes to persons with HIV/AIDS (5). Some sample questions on stigma are shown in Box 5. However, the results must be analysed carefully. Attitudes of care givers or potential care givers may differ from those who most likely will not have to care for an AIDS patient. Attitudes of women (who are often care givers) and men (generally not care givers) should be considered separately.

Several sources can be used to obtain data on the indicators listed earlier in the chapter. Most input and output indicators – for example, the number of condoms received in the district during a calendar year or the number of counsellors trained and active – can be derived from simple bookkeeping. Indicators of effects generally require a survey, which could be carried out either among a particular population (e.g. secondary school children) or in a random sample of the whole population. More detailed information on preparing and conducting surveys can be found in a World Health Organization manual

Box 5. Survey questions on stigma

1a	Would you be willing or not willing to take care of a female family member with AIDS?	Willing 1 Not willing 2 Do not know 3
1b	Would you be willing or not willing to take care of a male family member with AIDS?	Willing 1 Not willing 2 Do not know 3
2a	Should a woman who knows she is infected with HIV be entitled to keep this fact secret from her husband or should she tell him?	Entitled to keep secret 1 Should be revealed 2 Do not know 3
2b	Should a man who knows he is infected with HIV be entitled to keep this fact secret from his wife or should he tell her?	Entitled to keep secret 1 Should be revealed 2 Do not know 3
3	Should persons who know they are infected with HIV be entitled to keep this fact secret from the community where they live or should this information be revealed?	Entitled to keep secret 1 Should be revealed 2 Do not know 3
4	If you were to find out that you are infected with HIV, would you tell your friends or family?	Not tell anybody 1 Tell my friends 2 Tell my family 3 Tell friends and family 4 Do not know 5
5	Should persons with HIV who work with other people, such as in a factory or hospital, be allowed to continue their work or not?	Allowed 1 Not allowed 2 Do not know 3

on evaluating a national AIDS programme (5).

The health information system being used to collect routine data can be used to provide some data on the course of the epidemic in the district. Such data are collected in health facilities according to standard national procedures and are usually fed into a national health and management information system. Local analysis of levels and trends in the health facilities is an essential but often neglected component (3).

In most countries AIDS is a notifiable disease, but in Africa reporting of AIDS cases tends to be grossly inadequate. In part this is due to difficulties in making the diagnosis (for example, tests for HIV may not be available). This problem can be partially (but *only* partially) solved by using the WHO clinical case definition for AIDS (see Chapter 4 on epidemiological methods). For instance, in Rwandan health facilities the sensitivity of the clinical case definition was found to be only 33%, and in Mwanza only 27% (8, 9). In other words, using the clinical case definition alone, only one-fourth to one-third of HIV-positive patients were identified. Underreporting of AIDS may also be due to delayed

or incomplete reporting to the central level. However, it is to the advantage of a district to monitor trends in AIDS admissions and deaths in both adult and paediatric wards of the hospital(s). This data does not only show the importance of AIDS for hospitals, but also may make it possible to see trends over time. Data from an urban hospital in Mwanza, Tanzania (9), where the population prevalence of HIV among adults is estimated at 10–14%, illustrates the importance of HIV infection:

- 44% were HIV infected;
- 30% of adult admissions 15–44 were diagnosed as having AIDS on the basis of the expanded WHO clinical case definition, which uses clinical signs and symptoms plus serological data (HIV antibodies);
- 14% of adult admissions who were found to be HIV-positive died during their stay in hospital, compared to 4% mortality among those who were HIV-negative.

Simply monitoring the number of hospital admissions diagnosed with AIDS each year provides some information on the epidemic and its impact on inpatient health services. If HIV testing facilities are available, the number of HIV-positive adult admissions and the per cent of total adult admissions who are HIV infected are useful indicators.

Monitoring trends in tuberculosis incidence can also be a way to obtain an idea of changes in the HIV epidemic. Tuberculosis in Africa is on the increase, due to the HIV epidemic. For example, in 1994 it was estimated that in Tanzania 40% of all new tuberculosis cases were attributable to HIV infection. If the district has a well-established tuberculosis control programme with a good monitoring system, then data on tuberculosis incidence should be included as a part of monitoring HIV. Examples are given in the chapter on tuberculosis (Chapter 19).

Surveillance of STDs is also important. STDs are a public health problem in themselves, as well as an important factor contributing to HIV transmission (see Chapters 13 and 14, on STDs). A sentinel surveillance system may be the best option for collecting such data at district level. In such a system, a few sites are selected here the incidence of STDs, genital ulcer syndromes and genital discharge syndromes, along with drug sensitivity and treatment patterns, will be monitored. The RPR test can be used to test pregnant women for syphilis at sentinel surveillance sites; results can also be used to monitor trends over time.

Conclusions

Monitoring and evaluation should be an integral part of an HIV prevention and AIDS care programme. No matter what methods are used, it is essential to begin with baseline data that are as good as possible, plus clear objectives, strategies and targets. This provides a foundation for the design of a monitoring and evaluation system that uses indicators to assess the programme. At district level, the primary focus is on input and output indicators, and on indicators related to process – those associated with community involvement in the programme. If additional resources are available small-scale surveys can be conducted to collect information on indicators covering the effects of the inter-

Home-based care: the family has no fear for the person with AIDS.

ventions among the sexually active population. Staff involvement in all phases of the monitoring and evaluation process, combined with proper feedback and discussion of the results, is an important way of motivating them to collect data and make use of it.

With respect to the community, participatory monitoring is a low-cost method, for which an important goal is to stimulate the involvement of the target group and enhance their sense of 'ownership' of and commitment to the programme, and thus help to ensure immediate use of the results from monitoring or evaluation. Target group involvement may also make it easier to collect more reliable data on a difficult topic such as sexual behaviour, where other methods often fail.

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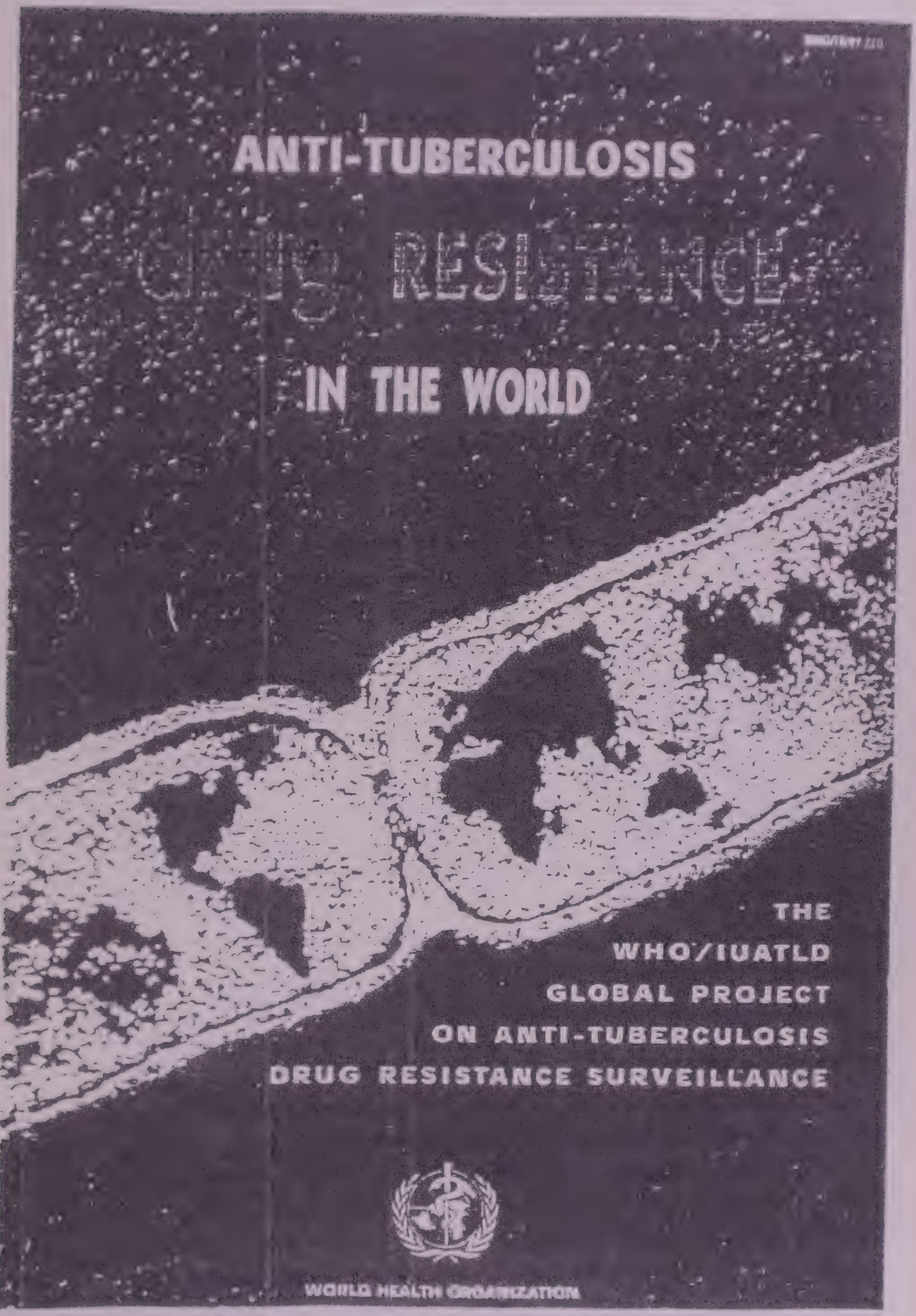
ANTI-TUBERCULOSIS
DRUG RESISTANCE
IN THE WORLD
THE
WHO/IUATLD
GLOBAL PROJECT
ON ANTI-TUBERCULOSIS
DRUG RESISTANCE SURVEILLANCE
WORLD HEALTH ORGANIZATION

SUMMARY

BACKGROUND

Antimicrobial resistance in previously susceptible organisms occurs wherever antibiotics are used for the treatment of infectious diseases in humans and animals. With increasing antibiotic use, and misuse, over the past decades, resistance has emerged in all kinds of micro-organisms — including *M. tuberculosis* — posing new challenges for both clinical management and control programmes.

Resistance of *M. tuberculosis* to antibiotics is a man-made amplification of spontaneous mutations in the genes of the tubercle bacilli. Treatment with a single drug — due to irregular drug supply, inappropriate prescription, or poor adherence to treatment — suppresses the growth of susceptible strains to that drug but permits the multiplication of drug-resistant strains. This phenomenon is called *acquired resistance*. Subsequent transmission of such resistant strains from an infectious case to other persons leads to disease which is drug-resistant from the outset, a phenomenon known as *primary resistance*.

Dramatic outbreaks of multidrug-resistant tuberculosis (MDR-TB) in HIV-infected patients in the United States and in Europe have recently focused international attention on the emergence of strains of *M. tuberculosis* resistant to antimycobacterial drugs. MDR-TB — defined as resistance to the two most important drugs, isoniazid (INH) and rifampicin (RMP) — is a potential threat to tuberculosis control. Patients infected with strains resistant to multiple drugs are extremely difficult to cure, and the necessary treatment is much more toxic and expensive.

Drug resistance is therefore a potential threat to the standard international method of TB control: the DOTS strategy ("Directly Observed Treatment, Short-course"). In 1994, WHO embarked on the project presented in this book to discover the extent of that threat. At that time, the available information suggested that levels of resistance may have been increasing in some settings, but methodological limitations prevented an

adequate assessment of the extent of the problem throughout the world and precluded meaningful comparisons between different countries.

WHO/IUATLD GLOBAL PROJECT ON ANTI-TUBERCULOSIS DRUG RESISTANCE SURVEILLANCE

In early 1994, the WHO's Global Tuberculosis Programme joined forces with the International Union Against Tuberculosis and Lung Disease (IUATLD) and started the Global Project on Anti-tuberculosis Drug Resistance Surveillance. The objectives of the project were to measure the prevalence of anti-tuberculosis drug resistance in several countries world-wide using standard methods and to study the correlation between the level of drug resistance and treatment policies in those countries.

The first step towards achieving the objectives was the development of common definitions and guidelines by world experts in 1994. These focused around three major principles: 1) surveillance must be based on a sample of TB patients representative of all cases in the country; 2) primary and acquired drug resistance must be clearly distinguished in order to interpret the data correctly; and 3) proper laboratory performance must be assured.

The second step was the establishment of a Global Network of Supranational Reference Laboratories (SRLs) to serve as the reference centres for quality assurance of drug-susceptibility testing (DST). Currently, the network comprises 22 SRLs. The third step was to organise a Working Group under the leadership of WHO with representatives of national tuberculosis programmes (NTPs) and research institutions from over 50 countries to implement surveillance projects at country level.

The First Phase of the Global Project described in this report includes results from 35 countries in five continents. Surveillance or surveys were conducted on approximately 50,000 tuberculosis cases sampled from areas representing 20% of the world's population. Each study enrolled 59 to 14,344 TB patients (mean 1,200). Testing for INH and RMP was accurate; resistance to ethambutol (EMB) and streptomycin (SM) was also evaluated. Overall agreement between the SRL and the various National Reference Laboratories was 96%. All countries, except three, distinguished between primary and acquired resistance.

MAIN FINDINGS

Primary drug resistance. This information is obtained from cases with effectively no previous treatment. It reflects the transmission of strains that were already resistant. The prevalence of resistance to any drug ranged from 2% (Czech Republic) to 41% (Dominican Republic), with a median value of 10.4%. Primary resistance to all 4 drugs tested was found in a median of 0.2% of the cases (range 0 to 4.6%). Primary MDR-TB was found in every country surveyed except Kenya, with a median prevalence of 1.4%, range 0 (Kenya) to 14.4% (Latvia).

Acquired drug resistance reflects more recent case mismanagement. The populations assessed for this are patients who have been treated for a month or longer in the past. As expected, the prevalence of acquired drug resistance was much higher than that of primary drug resistance. The prevalence of acquired resistance to any drug

ranged from 5.3% (New Zealand) to 100% (Ivanovo Oblast, Russia), with a median value of 36%. Resistance to all 4 drugs among previously treated patients was reported in a median of 4.4% of the cases (range 0 to 17%). The median prevalence of acquired MDR-TB was 13%, with a range of 0% (Kenya) to 54% (Latvia).

Overview of the global situation. These findings are probably an underestimate of the magnitude of the problem worldwide as the countries surveyed had better TB control than average. Resistance to tuberculosis drugs is probably present everywhere in the world. Certainly, MDR-TB is present in five continents, a third of the countries surveyed having levels above 2% among new patients. In Latvia 30% of all patients presenting for treatment had MDR-TB. The region of Russia surveyed had 5% of TB patients with MDR-TB. In the Dominican Republic, 10% of TB patients had MDR-TB. In Africa, Ivory Coast has also witnessed the emergence of MDR-TB. Preliminary reports from Asia (India and China) show high levels of drug resistance as well. In the State of Delhi, India, 13% of all TB patients had MDR-TB.

Correlation of prevalence of drug resistance with TB control policy and activities. An important finding of the study was the higher prevalence of MDR-TB in countries categorised by WHO as having poor control programmes. Similarly, the higher the proportion of retreatment cases (the result of a poor programme) and the higher the incidence of TB among children (an indicator of high TB transmission in recent years), the higher the levels of drug resistance. The use of standardised short-course chemotherapy regimens, on the other hand, was associated with lower levels of drug resistance.

CONCLUSIONS

1. Drug resistance is ubiquitous. The Global Project found it in all countries surveyed. The levels of resistance to INH are high, and continued failure to improve TB control will fuel multidrug resistance.
2. There are several "hot spots" around the world where MDR-TB prevalence is high and could threaten control programmes. They include Latvia, Estonia and Russia in the former USSR, the Dominican Republic and Argentina in the Americas, and Ivory Coast in Africa. Preliminary reports from Asia also show high levels of MDR-TB. Urgent intervention is needed in these areas.
3. There is a strong correlation between both the overall quality of TB control and use of standardised short course chemotherapy and low levels of drug resistance. A high prevalence of MDR-TB is the result of therapeutic anarchy. Half the countries or regions with the worst TB control had primary MDR levels above 2% , compared with one-fifth of those with moderate control, and none of the countries with the highest standard of TB control.
4. The MDR-TB level is a useful indicator of NTP performance. As shown by the Global Project and by previous experiences in Korea and New York, the prevalence of primary MDR-TB is a good "summary" indicator of the performance of NTPs in recent years.

RECOMMENDATIONS

A) Surveillance

For the future, the authors propose the following recommendations concerning surveillance:

1. The well established network of SRLs is a model for standardised surveillance of drug resistance and should be maintained as a global resource. Surveys using the SRL network need to be repeated in the same 35 countries around the year 2000 to determine MDR-TB trends over time.
2. Adequate assessment of the level of MDR-TB in large countries (China, India, Russia) requires expansion of surveillance activities beyond the regions studied. Areas not adequately covered during the first phase of the Global Project must be targeted.
3. Future surveys should collect and analyze individual data on age, HIV co-infection, and country of birth, and on the contribution of the private sector to drug resistance.

B) Management

1. Countries without the DOTS TB control strategy need to implement it. This is supported by the Global Project's finding of an association of low resistance and high quality TB control. Previous experience has also demonstrated falls in resistance, and even in MDR-TB, following the introduction of DOTS.
2. The Global Project did not directly address the issue of treatment regimens. Based on previous experience, however, no alterations to the first line treatment regimens recommended by WHO and IUATLD are yet required. For the management of drug-resistant TB, including MDR-TB, the reader is referred to "Guidelines for the Management of Drug-resistant Tuberculosis" (WHO/TB/96.210).

C) Research

1. The authors recommend research to:
   a) Assess the transmissibility and clinical virulence of MDR-TB compared to disease caused by drug-susceptible strains.
   b) To define the impact of MDR-TB on treatment outcomes under programme conditions in developing countries.
2. Pharmaceutical companies are urged to develop new anti-TB drugs. The prime need for such drugs is to make DOTS more efficient and to shorten the duration of treatment thus making resistance less likely to emerge.

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A special supplement to CHILD HEALTH DIALOGUE April-June 1996

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Glossary

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Symptoms

TB in children

4-5 Principles of TB control

Household transmission of TB to children

TB and women

6-7 How to detect and diagnose TB

Dangers of TB in children

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12 Making TB programmes work

13 Preventing TB transmission in health facilities

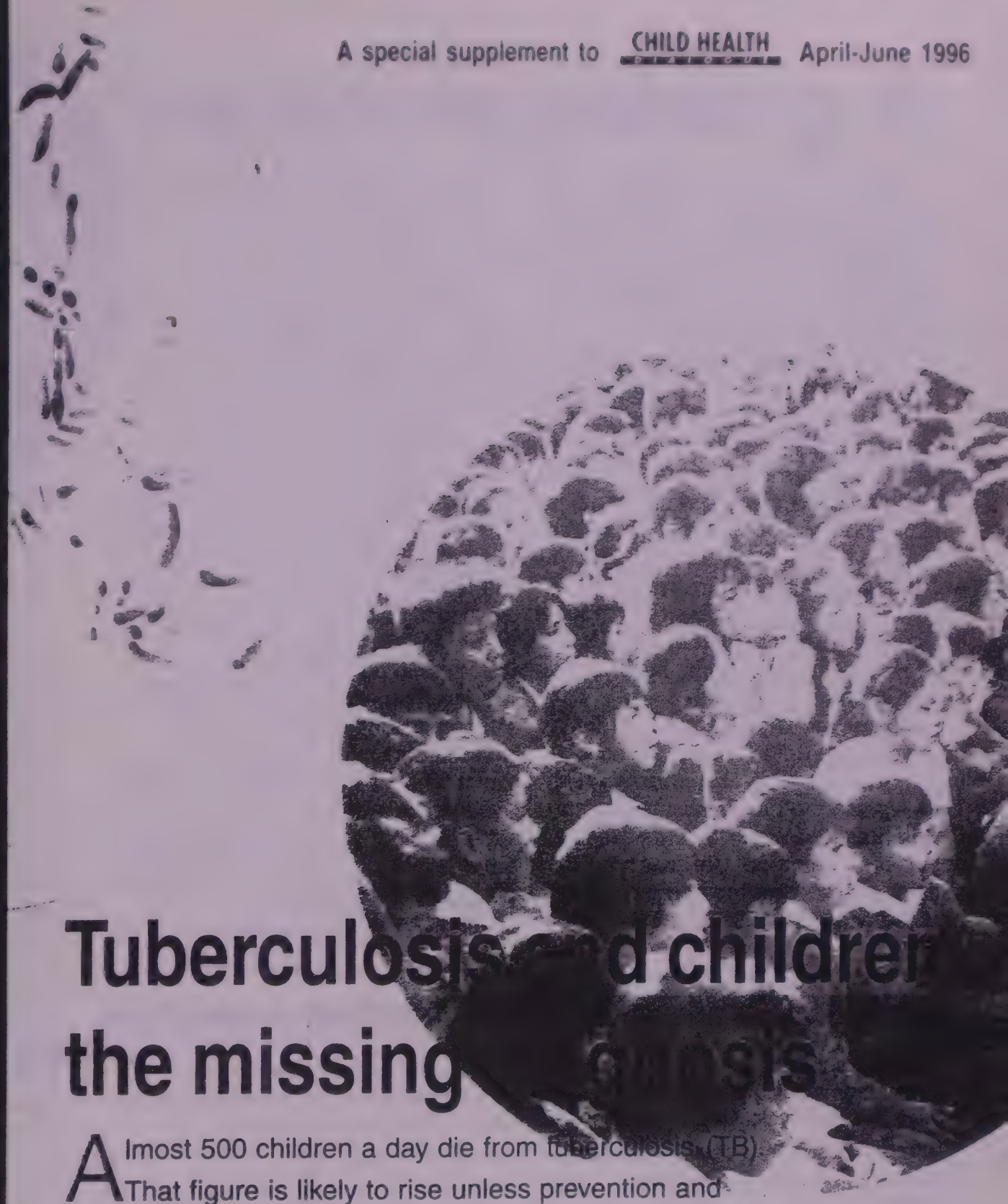
14 Helping communities control TB

15 Tuberculosis treatment game

16 Key points

Resources

Acknowledgements

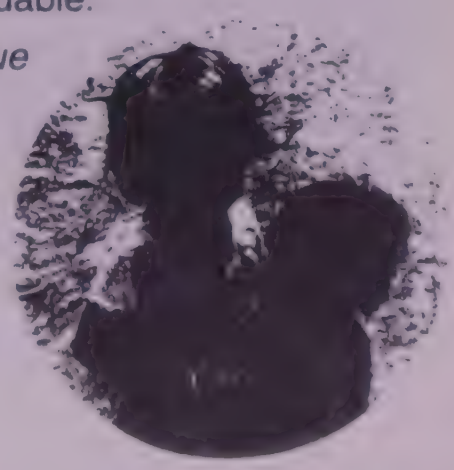


Tuberculosis and children the missing epidemic

Almost 500 children a day die from tuberculosis (TB). That figure is likely to rise unless prevention and treatment efforts are increased. More people, in more countries, are at risk of TB than ever before.

Tuberculosis creates more orphaned children than any other infectious disease. It is also the leading killer of women, surpassing all causes of maternal mortality. TB deaths among women have major implications for child survival and for family welfare.

TB is difficult to diagnose in children. However, effective control and treatment is both possible and affordable. In this special supplement, *Child Health Dialogue* looks at the ways to prevent the spread of TB to children and how to treat those who have the disease.



A growing problem

Two billion people – one-third of the world's population – are infected with tuberculosis (TB). Every year three million people die from TB and eight million become sick with TB disease, mostly in developing countries. The World Health Organization (WHO) predicts that the number of new adult TB cases will increase to over 10 million a year by 2000. Despite the development of effective drugs, TB causes more deaths in adults than any other infectious disease.

TB also affects children, directly and indirectly. Although information about the number of children with TB is scarce, an estimated 170,000 children a year die from the two most severe forms of the disease – tuberculous meningitis and disseminated disease (often referred to as miliary tuberculosis). The increase in TB will place more children at risk. Children aged under two years are especially vulnerable. Children also suffer if their mother or father is sick or dies because of TB. No other infectious disease creates as many orphans as TB.

Factors affecting TB

There are three main reasons why TB is a growing problem:

- increasing poverty
- neglect of TB programmes
- the spread of HIV (human immunodeficiency virus).

TB spreads easily in overcrowded, badly ventilated places and among people who are undernourished. This has led to TB being known as a disease of poverty. The rise of TB in the USA and Europe is related to increased homelessness and poverty, and to deteriorating public health systems. In developing countries, urbanisation, overcrowding and economic constraints have put millions at risk of catching TB. At the same time, overburdened health systems have faced severe cuts and wide-ranging reforms. Access to vital services for the poorest sectors of the population has declined.

Effective TB control requires a properly functioning, well-managed health service with good diagnostic facilities, trained staff and available drugs. But financing TB programmes has not been a priority.

There has also been little community education to tell people about TB symptoms, reduce discrimination and encourage them to seek treatment. This means that people with infectious TB do not seek treatment and continue to infect others, including children. Someone with active TB will infect an average of 20 to 28 other people before he or she either dies or recovers from the disease.

In some cultures there is a stigma attached to TB. When someone has TB, his or her whole family may suffer prejudice in the community.

The HIV epidemic contributes to the increase in TB in young children in some countries. Worldwide the number of people infected with both HIV and TB is rising and will reach four million by the year 2000. HIV infection stops the immune system working properly, making it much more likely that infectious tuberculosis will develop. This means more people in the community will have active TB disease and will be infectious to others, including children. Infants who are infected with HIV before or at birth are very vulnerable to a range of infections, including TB, and the prognosis for children with both infections is poor. (See page 10 on HIV and TB in children.)

But TB is both avoidable and curable. Health workers need to know how to identify and treat TB. Its spread

TB creates more orphans than any other infectious disease.

GLOSSARY

Tuberculosis (TB) – infectious disease caused by *Mycobacterium tuberculosis*, which forms small granules (tubercles) in whichever body organ the bacteria infects. The tubercles multiply and change so that they eventually can destroy the organ.

Pulmonary tuberculosis – tuberculosis affecting the lungs

Extra-pulmonary tuberculosis – tuberculosis affecting parts of the body other than the lungs

Disseminated (generalised) disease – (often referred to as miliary disease) tuberculosis affecting many locations in the body at the same time, resulting from spread or dissemination of the bacilli through the body in the bloodstream

Tuberculous meningitis – tuberculosis of the covering of the brain and spinal cord (meninges)

Bacillus (more than one bacillus = bacilli) – a type of rod-shaped bacterium (germ)

Acid Fast Bacilli (AFB+) – bacilli which stain red by the Ziehl Neelsen method. The stain cannot be removed by using acid, and is characteristic of the tuberculosis bacillus and other mycobacteria

Sputum – substance coughed up from the lungs

Sputum smear test – a laboratory technique to screen sputum for TB. Acid fast bacilli are identified by the Ziehl Neelsen method and counted using a microscope

Smear positive pulmonary TB – at least two initial sputum smears positive for AFB OR one AFB positive smear and one positive culture

Smear negative pulmonary TB – at least three sputum negative smears but with symptoms suggestive of TB, chest x-ray abnormalities OR diagnosis based on positive culture but negative AFB sputum tests

Preventive chemotherapy (chemoprophylaxis) – giving anti-tuberculosis drugs to a person with symptomless TB infection to prevent progression to active TB disease

can be prevented by proper treatment of infectious patients with anti-tuberculosis drugs. With correct treatment, adults and children with TB are no longer infectious after two to three weeks and almost all can be cured. Children can be protected against the most severe forms of TB by BCG (Bacille Calmette-Guerin) vaccination, and they are less likely to get TB if infectious adults are detected and treated.

SYMPTOMS OF TB

Adults with pulmonary TB have chest pain and severe cough, sometimes with blood in the sputum. Exhaustion, night sweats, fever and weight loss are symptoms of both pulmonary and extra-pulmonary TB.

Signs and symptoms of TB in **children**, however, are non-specific. In other words they are similar to symptoms resulting from a number of childhood illnesses. Children with TB may have cough, fever or diarrhoea for more than a month, unexplained weight loss, enlarged glands, fits and neck stiffness. (See pages 6-7 for more detailed information.)

TB IN CHILDREN

Primary infection, in the lungs initially, usually occurs in under fives. A child with primary infection often has no symptoms of illness, but abnormalities can be seen on chest x-rays. The younger the child, the greater the risk of spread of the TB germs to other parts of the body and of severe complications.

These types of *extra-pulmonary TB* include *tuberculous meningitis* – which affects the brain, and *disseminated disease* – which affects many parts of the body at the same time.

Other *extra-pulmonary* sites affected by TB are the lymph nodes, bones and joints (see pages 6-7). Tuberculous pleurisy (inflammation of the membrane covering the lung and inner surface of the ribs) is also classified as extra-pulmonary TB.

Pulmonary TB is more common in adults than in young children. When it develops depends on the age at which the child was infected – most do not develop pulmonary TB until adolescence.

What is tuberculosis?

Tuberculosis is nearly always caused by infection with the bacillus *Mycobacterium tuberculosis*. TB can affect the lungs – this is pulmonary TB. The TB germs can also enter the bloodstream and spread to other organs in the body – this is extra-pulmonary TB. Pulmonary TB is more common in adults; extra-pulmonary TB is more frequent in children. Extra-pulmonary TB is not infectious.

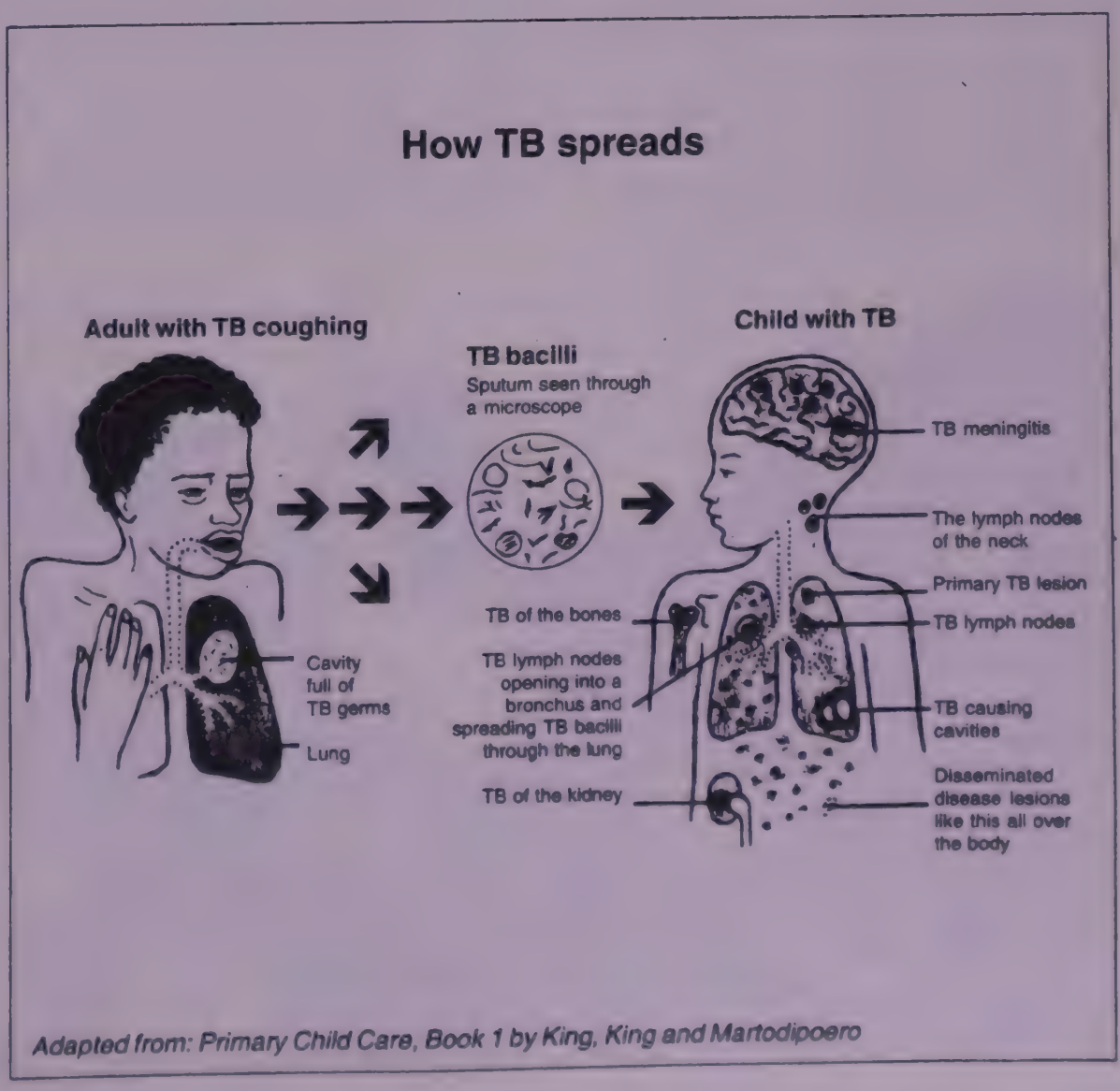
There is a difference between TB infection and TB disease. Someone exposed to TB germs who becomes infected has tuberculosis *infection* (or latent TB). Sometimes the infection progresses to TB *disease* (tuberculosis, active tuberculosis or active disease).

Once infected with TB, a person remains infected for the rest of his or her life. Most people do not develop tuberculosis disease. In a healthy individual, the body's defences (immune system) stop the germs from multiplying enough to cause illness. The immune system of a young child is less well developed than that of an adult. This allows TB to spread to sites throughout the body during initial infection. TB can later begin to grow at these sites, especially if the child's immune system is not working well.

The risk of developing active disease depends on a child's nutritional status. Poorly nourished children are at greatest risk. Children who have measles and whooping cough (pertussis) also have less resistance to TB germs. They are more likely to develop active disease.

How is TB transmitted?

Adults are the main source of TB infection in the community. Active pulmonary TB is the only form of the disease which is infectious, spreading from person to person via the air. The lungs of a person with active pulmonary disease may develop cavities (spaces) which are full of TB germs. When the person coughs or sneezes, large numbers of TB germs from the lungs are sprayed into the air in tiny droplets. Family, friends, colleagues and health workers who have close contact with someone who has infectious TB are at greatest risk.


How TB spreads
Adult with TB coughing
Cavity full of TB germs
Lung
TB bacilli
Sputum seen through a microscope
Child with TB
TB meningitis
The lymph nodes of the neck
Primary TB lesion
TB lymph nodes
TB causing cavities
Disseminated disease lesions like this all over the body
TB of the bones
TB lymph nodes opening into a bronchus and spreading TB bacilli through the lung
TB of the kidney

Adapted from: Primary Child Care, Book 1 by King, King and Martodipoero

Principles of tuberculosis contro

Detection and treatment

People can only spread TB to others when they have active disease. So the key principles of TB control are:

- **identifying people with infectious TB** (called case finding)
- providing effective supervised **treatment**.

By detecting and treating infectious TB, health workers can prevent its spread to other adults and to children.

Identifying cases

Case finding prioritises identifying people with smear positive active TB because they are the most important source of infection in the community.

Passive case finding means diagnosing infectious smear positive people who come to health facilities with symptoms of TB. For passive case finding to identify as many infectious cases as possible, people need to know about the symptoms of TB and the availability of effective treatment, and health workers need good diagnostic and communication skills. In some countries, TB is more likely to be detected and treated in men than in women (see page 5). But a child may be at higher risk of infection if his or her mother has TB, because of potential transmission during pregnancy and closer contact in infancy. So health workers need to look out for TB symptoms when women visit health facilities.

Active case finding means trying to reach all those in a community who may have TB disease. However, it is less cost-effective than passive case finding and is not recommended for TB programmes, except in the case of children in contact with a source of infection. TB programmes should concentrate on proper detection and treatment for people who come forward with symptoms.

Treatment and supervision

Anti-tuberculosis drugs are about 95 per cent effective when prescribed and taken correctly. Treatment is based on a combination of drugs given for several months, in two phases: an **initial intensive phase** and a **continuation phase**.

Adults may find it difficult to take anti-tuberculosis drugs for a long period of time. Making sure that a young child takes drugs every day and completes a course of treatment requires patience and persistence from the parents and careful follow-up and support by health workers. A well supervised programme with directly observed therapy, which means watching the patient take the drugs, can help (see page 11). It is also very important to explain the treatment and dosages to parents. When parents understand this, most will ensure that their children receive correct treatment.

BCG vaccination

The BCG (Bacille Calmette-Guerin) vaccine does not reduce the risk of getting TB, so it has a limited role in TB control. But it can protect young children against the most severe and life-threatening forms of TB disease in childhood, such as tuberculous meningitis and disseminated disease. Where TB is common, BCG vaccination is important in preventing serious disease in young children. BCG vaccination usually leaves a scar which tells a health worker that a child has been vaccinated with BCG.

BCG vaccine should be given to young children as early in life as possible, preferably immediately after birth, and before the age of 12 months. The only exception is if the mother is sputum smear positive when the baby is born. In this situation the infant should be given preventive chemotherapy (see page 5 and pages 8-9), and BCG vaccination should be postponed until preventive chemotherapy ends. There is no value in giving BCG to children aged over two years. The national immunisation programme can provide detailed information about BCG vaccination.

BCG vaccination protects young children from the most severe forms of TB.

HOUSEHOLD TRANSMISSION

Children with TB are usually infected by a sputum positive adult in their immediate household. Contact screening is therefore essential to detect early infection in young children.

In Malawi, 282 children aged under six years who were household contacts of sputum positive adults were screened for TB. The screening found 180 of the children (63.8 per cent) had evidence of TB (based on consistency of symptoms, x-ray findings, tuberculin test reaction and responses to treatment). This was an extremely high transmission rate. The study concluded that child contact tracing is essential in families where an adult has infectious TB given the considerable risk of the children developing TB disease.

Giving BCG vaccine to HIV positive infants who have severe immunodeficiency may increase complications or result in illness caused by the vaccine itself. However, in most HIV positive infants, the benefits outweigh the possible risks. BCG vaccine should be given to all infants, including those who may be HIV positive, with the exception of those with symptomatic HIV disease.

Preventive chemotherapy

Preventive chemotherapy (or chemoprophylaxis) means giving anti-TB drugs to someone with TB infection (or with very high risk of being infected) to prevent progression to active disease. Young children and infants in contact with someone who has active disease are at high risk of TB infection. The risk of progression to active disease is highest in those who have been recently infected with TB – which is more likely in young children and infants.

So in developing countries, preventive chemotherapy is only usually recommended for:

- young infants whose mothers have active pulmonary TB
- young children under five who have no TB symptoms but live in the same household as a person with infectious TB.

The standard WHO recommendation for preventive chemotherapy is 5mg/kg body weight of daily isoniazid for three months. Preventive chemotherapy should only be given to children when it is certain that they do not have active TB disease. Children with active TB require full and correct treatment.

Special needs of children

The priority given in TB control to identifying and treating infectious, usually adult, cases, can mean that the needs of children are ignored. Because children with TB are not usually infectious to others, rarely produce smear positive sputum, and pose less risk to the community, they are not always identified and treated. Health workers need to be aware that TB can be life-threatening for very young children. Children living with adults who have active disease should be checked carefully and given preventive chemotherapy, BCG or treatment according to their condition. Children with tuberculous meningitis or disseminated disease need hospital treatment urgently.

Tuberculosis and women

One million women a year die from TB. This makes TB the leading single infectious cause of female deaths in the world. TB kills more women each year than all causes of maternal mortality combined.

TB affects the majority of women in the most productive years of life, those in which they raise children and perform other work: in the labour force, in the household or in the fields.

Because women have such close contact with their children, a mother sick with TB poses a real threat to her children. It is common for mothers unwittingly to infect their children with TB before dying of the disease themselves.

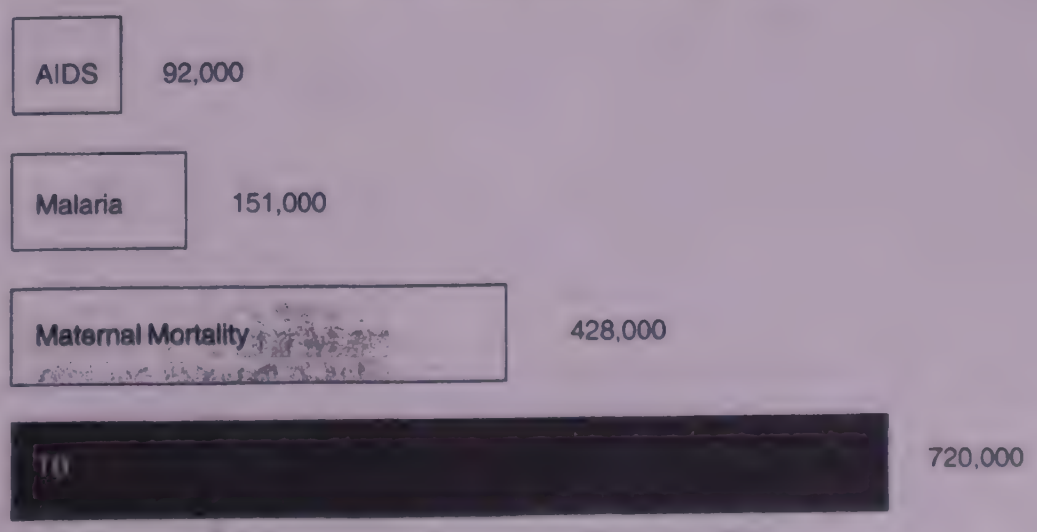
At least one-third of the six million women sick with TB at any given time die because they are undiagnosed or receiving poor treatment. There are a number of reasons why women do not seek or receive treatment, including:

- lack of time because of work and family demands
- lack of money and transport
- the need to get permission or be accompanied by a male member of the family to visit a health centre
- stigma (some forms of TB can cause infertility)
- poor education which limits access to information about symptoms and treatment of active disease
- lack of female health workers in cultures where female modesty is important.

TB deaths among women have major implications for child survival, economic productivity and family welfare. TB programmes and health workers need to be more responsive to the needs of women if they are to increase case finding and treatment.

TB is a leading killer of women

(Number of deaths worldwide in 1990)



Adapted from: WHO Report on the Tuberculosis Epidemic 1996

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How to detect and diagnose TB

The main tools for identifying people with TB (detection) are:

- clinical symptoms
- tuberculin testing
- chest radiography (x-ray).

The main tool for diagnosis is:

- Sputum smear microscopy (and sometimes culture of bacteria).

TB treatment in adults should not start on the basis of clinical evidence alone. The diagnosis should be confirmed by sputum smear microscopy to identify infectious cases of pulmonary TB.

Adults

Health workers should suspect pulmonary TB in adults who have the following symptoms:

- cough for more than three weeks
- blood in the sputum
- chest pain for more than a month
- increasing weakness and loss of weight
- past history of TB or treatment for cough.

Children

Health workers should suspect TB in children under five who:

- are in close contact with someone who has had a positive sputum smear
- have a strongly positive tuberculin test
- have clinical signs and symptoms.

The diagnosis should be confirmed on the basis of further tests, usually x-ray.

In many places further tests are not possible, so health workers may need to decide if a child has TB based on history, physical examination and clinical symptoms. It is reasonable to assume that a child with clinical symptoms, a positive tuberculin test and who is in contact with an infectious source has TB.

Diagnosis in children is more difficult than in adults because TB in children is often limited in the lung or is located outside the lung (extra-pulmonary). The available diagnostic tools – such as sputum smear microscopy – are less helpful for younger children in particular. For this reason, cases of TB in children may be undetected and under-reported.

X-ray can be helpful but the results depend on the quality of the x-ray and also need to be looked at along with clinical signs. Reading x-ray results in children is a special skill and can be difficult as the findings may not show clear signs of TB.

A child with suspicious symptoms should have a **tuberculin test**. A strongly positive test in a child with normal weight and height means that the child has been infected with TB bacilli but does not necessarily mean that he or she has TB disease. In a young child, infection will have occurred recently and there is therefore a high risk that he or she will develop TB disease. In malnourished children or those with HIV infection, the test result may be negative. Such children should still be treated for TB if it is suspected on the basis of clinical symptoms or suspected on x-ray, but

DANGERS AND SPECIFIC SIGNS OF TB IN CHILDREN

The two forms of TB which are most dangerous to children are disseminated disease and tuberculous meningitis, which affect the:

Whole body

Disseminated disease is a systemic illness because TB affects many parts of the body at the same time.

Signs steady high fever, rapid pulse, nausea, vomiting and diarrhoea, cyanosis (blueness of the lips) and occasionally respiratory distress.

Brain or spine

Tuberculous meningitis affects the brain and the central nervous system.

Signs irregular fever, irritability, headaches, vomiting attacks, stiffness of the neck, increasing drowsiness. Diagnosis is confirmed by chest x-ray and lumbar puncture. If clinical signs and x-ray suggest meningitis, start treatment immediately, do not wait for the results of the lumbar puncture.

Tuberculosis can also affect other parts of the body including the:

Lungs

Children do not always show dramatic symptoms, unlike adults. There may not always be a cough or production of sputum, and sputum rarely contains blood.

Signs may include pain or fluid on one side of the chest.

Bones and joints

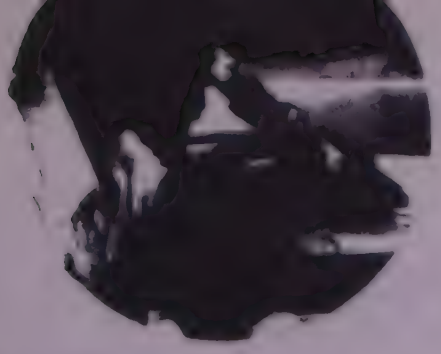
TB can affect the spine, hips; knees, and bones of the foot and hands.

Signs swellings at the joints (not hot or feverish as with a septic infection), stiff back, spinal hump, a limp when walking, unwillingness to bend the spine, slow onset of weakness in one arm or leg.

Skin or mucous membranes

Signs usually a painless swelling in the lymph nodes near the site of infection. For example, if the mouth is infected, the lymph nodes in the neck become swollen. TB can also cause the lymph nodes in the groin or armpit to swell.

Less commonly affected are the *abdomen*, which produces a lump or swelling, and the *eyes*, which if infected become watery and irritable with enlarged lymph nodes in front of the ear.



an expert opinion is necessary. A weak positive result can occur after BCG vaccination.

A negative test can be useful in excluding TB in children. The test might be false negative if the child is quite ill or malnourished. If the test remains negative when the child gets better, it is almost certain that the child does not have TB, provided he or she does not have HIV infection.

Clinical signs and symptoms in children are non-specific, so careful physical examination and taking a history are very important.

General signs to look for include:

- decrease in weight without any obvious explanation
- loss of appetite and failure to thrive and gain weight
- two or more episodes of fever without any obvious cause such as malaria or acute respiratory infection
- swollen, painless swellings affecting the lymph nodes, especially in children with HIV
- cough or wheeze for more than two weeks.

Check first that the child does not have malaria or another infectious illness that could be causing the symptoms.

Specific signs vary according to the site of the infection (see box on page 6).

REMEMBER

- TB and malnutrition often go together, but the majority of children with malnutrition do not have TB.
- Slow onset of typhoid fever can resemble TB.
- Chronic infections of the respiratory system can be present at the same time as TB.
- Malaria and TB can also be present at the same time or be mistaken for one another.
- Other causes of swelling of the lymph nodes such as lymphoma (tumour of lymphoid tissue) can resemble TB.
- A child may have more than one infection, for example measles, HIV or acute respiratory infection (ARI).

DETECTION AND DIAGNOSTIC TOOLS

In children, the two main detection tools used are tuberculin skin testing and x-ray.

Tuberculin skin testing

- measures the body's response to TB by showing whether TB antibodies are present
- uses a standardised injection of purified tuberculin (from a reliable source)
- is a useful indicator of infection and probable disease in young children
- is relatively easy to perform and interpret.

How to do the test Inject purified tuberculin between the layers of the skin (intradermally). Ensure that the injection goes *into* and *not under* the skin (subcutaneous). Look at the reaction to the test at the site of the injection 48-72 hours later. Measure the diameter of the widest point of the raised, thickening mark on the skin (induration) at the injection site. Record the result in millimetres (rather than as positive or negative). To help do this accurately, mark the edges at the widest point with a pen and measure the exact distance between the two points. A strongly positive test, with an induration of 10mm or more, indicates past infection with TB.

Chest radiography (x-ray)

- is expensive and usually only available in hospitals
- is difficult to read and may lead to both over- and under-diagnosis of TB, because many diseases can look like TB on x-ray and because extra-pulmonary TB or the early stages of pulmonary TB will not be detected
- is not a reliable detection tool for most childhood TB.

Diagnostic tools

The two main effective diagnostic tools for TB in adults – sputum smear microscopy and culturing – generally are not useful for detection or diagnosis in children.

Sputum smear microscopy

- is the most useful tool in low-income countries for diagnosing infectious pulmonary TB in adults
- is cheaper, easier and more reliable than other methods
- requires well-trained laboratory workers and well-maintained equipment. Poorly trained staff or inadequate equipment can lead to over-diagnosis of smear negative and under-diagnosis of smear positive cases.

How to do the test Collect three sputum samples from the person with suspected TB. Obtain the specimens within 24 hours: one on the spot, another early the next morning, and the third when the patient returns to the health centre. Prepare and examine each specimen under a microscope. If TB germs can be seen in the sputum, the person is sputum smear positive. This means that he or she has a large number of TB germs in the lungs and can therefore easily spread TB. Two positive sputum smears are enough to confirm the diagnosis of TB. If the first two smears are positive, there is no need to examine the third smear. If the first smear is positive and the second is negative, examine the third smear. One negative smear result is not enough to exclude a diagnosis of TB.

Culturing

- involves sending a specimen of sputum to a specialised laboratory where TB bacteria, if they are present, can be 'grown' or cultured
- is more sensitive than sputum smear microscopy although examination of three smears is as effective as one culture
- is expensive and in many countries facilities and personnel to do it are not available
- the results can take several weeks to come back; this delays confirmation of the diagnosis and the start of treatment
- can be useful to test TB bacteria for drug resistance and sensitivity in patients who are not responding to treatment
- is also useful for smear negative cases where active TB is suspected.

New diagnostic tests under development

Two diagnostic tests which make use of nucleic acid probes to identify the TB bacteria have recently been developed. They can confirm a diagnosis in about six hours instead of several weeks and have the same accuracy as a culture. These tests have successfully detected the bacteria in a variety of samples including sputum, cerebrospinal fluid and blood. Currently, the best diagnostic results are obtained with a positive sputum smear. Hopefully, simpler and less expensive versions of the test will be developed which should make TB diagnosis, even in children, easier and quicker.

Treatment of tuberculosis

Children with TB need treatment although they are usually non-infectious and not a risk to the community. If a child has TB, he or she should start treatment straight away. Children with TB improve very quickly and can be cured if they are given proper treatment.

The principles of TB treatment are ensuring that drugs are:

- prescribed in an appropriate combination to prevent development of resistance
- prescribed in the right dosage
- taken regularly under supervision
- taken for a sufficient period of time.

The most commonly used first-line anti-tuberculosis drugs are: isoniazid (H), rifampicin (R), ethambutol (E), pyrazinamide (Z), streptomycin (S), and thiacetazone (T). Some of these drugs are available in combined preparations, for example isoniazid with rifampicin (RH); isoniazid with thiacetazone (TH); and isoniazid with ethambutol (EH). Treatment regimens (drugs, dosages and length of treatment) which contain both isoniazid and rifampicin are the most effective. Because rifampicin is such a useful anti-TB drug, it should not be used to treat other diseases.

Most countries now have national guidelines recommending the treatment regimens to be used for tuberculosis. These guidelines should be followed by both private and government health workers. If there are no national guidelines, follow WHO TB treatment guidelines.

Length of treatment

Until recently the standard treatment regimen was 12-18 months. However, people are not likely to complete such a long course of treatment. This means they are not cured and continue to infect others in the community. Regimens can be shortened to six to eight months if they include rifampicin. These regimens are called Short Course Chemotherapy (SCC).

Since the late 1980s, WHO has encouraged national TB programmes to introduce SCC regimens which include rifampicin. Because of financial constraints, many developing countries still use the old standard 12-month course. However, the drugs for the short treatment are only a little more expensive. Successful completion of treatment is higher and better cure rates are achieved. This means that SCC regimens are a better use of resources.

Phases of treatment

Treatment includes:

- an **initial intensive phase** – in this phase, a combination of three or more drugs is given to eliminate as many TB bacilli as possible and prevent the development of drug resistance. The initial phase of therapy should last for a minimum of two months. The child should be checked carefully after two months and prescribed the treatment for the continuation phase, according to his or her weight.
- a **continuation phase** – in this phase, fewer drugs are given but the treatment needs to be continued for long enough to ensure that the patient is cured. Depending on the regimen, the continuation phase can be four or six months.

TREATMENT REGIMENS FOR NEW CASES OF TB

Initial intensive phase
TWO MONTHS
Daily dosage
Rifampicin (R) 10mg/kg AND
Isoniazid (H) 5mg/kg AND
Pyrazinamide (Z) 25mg/kg
In severe forms of TB or in smear positive pulmonary TB a fourth drug is usually given:
Ethambutol (E) 15-20mg/kg (children: 15mg/kg)
OR
Streptomycin (S) 15mg/kg

Continuation phase
FOUR MONTHS
Daily dosage
Rifampicin (R) 10mg/kg AND
Isoniazid (H) 5mg/kg
OR
Intermittent dosage (three times a week)
Rifampicin (R) 10mg/kg AND
Isoniazid (H) 10mg/kg

OR

SIX MONTHS
Daily dosage (See Notes)
Ethambutol (E) 15-20mg/kg (children: 15mg/kg) AND
Isoniazid (H) 5mg/kg
OR
Thiacetazone (T) 2.5mg/kg AND
Isoniazid (H) 5mg/kg

Adapted from: Tuberculosis control workshop report, Geneva, Oct. 1995 WHO/TB/96.199

Notes:

1. In the past a dose of 10 mg/kg of isoniazid has been used but this is not recommended by WHO or the International Union Against Tuberculosis and Lung Disease (IUATLD) except in the early stages of treating tuberculous meningitis.
2. Issues to consider when using streptomycin are:
   a. possible damage to hearing
   b. streptomycin has to be give by injection which is painful for children
   c. there is a risk of spreading HIV or hepatitis viruses unless there is very careful sterilisation of injecting equipment
   d. syringes and needles add to the cost.
3. Ethambutol given for long periods can affect vision and younger children are unable to report problems with their sight.
4. Thiacetazone may no longer be recommended in areas where HIV infection is common because of serious and sometimes fatal side effects, where the skin blisters and peels. Thiacetazone should be avoided in children with HIV infection.

For these reasons, **the best regimens in children are those based on rifampicin, isoniazid and pyrazinamide.**

Intermittent therapy

Intermittent therapy means taking anti-tuberculosis drugs three times a week instead of daily. There is no difference between intermittent and daily regimens in terms of the final outcome. But intermittent regimens may be less suitable for young children because they have to take a larger number of tablets at each dose than with daily regimens.

Treatment regimens for children

Children who require treatment fall into three categories:

- children with symptoms who have pulmonary or extra-pulmonary disease such as bone or joint TB – who should be treated as out-patients according to national guidelines
- children who are seriously ill with extensive pulmonary disease, disseminated disease or tuberculous meningitis – who require immediate hospital admission for treatment
- children without symptoms but who are known to have been infected recently or are at high risk of infection through contact with an infected source – who require preventive isoniazid chemotherapy.

SIDE EFFECTS

Anti-tuberculosis drugs are generally well-tolerated in children if they are given in the recommended dosages. Serious side effects are rare. Minor side effects do not mean that treatment should be stopped, but parents need reassurance and to be warned about possible side effects.

During clinic or home visits, health workers should ask the mother whether the child has had any adverse reactions. If a child develops any of the following side effects, health workers should stop the treatment and refer him or her to a doctor immediately:

- yellow jaundice (hepatitis)
- problems with urinating or suspected kidney failure
- shock
- rash and fever
- vision problems.

Minor side effects include nausea, vomiting, red or orange body fluids, temporary itching and inability to sleep. If any of these occur, check the drug dosages and monitor the child's condition.

PREGNANCY AND INFANTS

Management of the newborn depends on the mother's TB status. TB can be transmitted to the unborn child in rare cases. Pregnant women with TB should be identified and treated, for the sake of their own health as well as that of their child. Pregnant women with active pulmonary TB do not always show symptoms, so health workers should take a careful history during antenatal care. Infants infected during pregnancy may appear well at birth but stop gaining weight about three weeks after birth.

- Pregnant or breastfeeding women who have TB should be treated with short course chemotherapy.
- Rifampicin, isoniazid, pyrazinamide and ethambutol are safe for use in pregnant women.
- Streptomycin should **not** be given to pregnant women as it may cause deafness in the baby.
- If the mother is sputum smear negative at the time of birth, the infant should be vaccinated with BCG but needs no treatment.
- If the mother is sputum smear positive at the time of birth and the infant is well, he or she should be given preventive chemotherapy (isoniazid 5mg/kg in a single daily dose) for three months, but not BCG. Give a tuberculin test after three months. If the result is negative, stop the isoniazid and give BCG. If the result is still positive continue preventive chemotherapy for a further 3 months. If the result is negative vaccinate the infant with BCG.
- If the infant is unwell with TB symptoms give full anti-tuberculosis treatment.
- If possible, do not separate the infant from the mother.
- Breastfed children should continue to breastfeed.

The basis of treatment for children is the same as for adults (see page 8). The regimen should be based on the child's pre-treatment weight and adjusted if necessary after the first two months of treatment.

Medicines in tablet form, such as isoniazid, can be crushed and mixed with a small amount of breastmilk or fruit juice, to make them easier to swallow for small children.

General care and treatment

In addition to treating TB, health workers should check whether a sick child has any other infections that need treatment. Dealing with other infections can help the child to fight off TB and get better more quickly. Malnutrition also reduces the body's ability to fight infections. Parents should encourage a sick child to eat frequent nutritious meals. Making sure a child gets enough good food helps him or her to get better quickly.

How to assess cure?

In adults, cure of active pulmonary TB is assessed by sputum smear changing from positive to negative. The best way to assess success of treatment in children is improvement in general well-being and weight gain. The emphasis in children should be on completion of treatment – cure is almost always achieved if a child completes the full treatment.

Relapse and failure

Relapse and failure are unusual in children. Failure to respond to treatment in children is usually because of incorrect diagnosis or not taking the drugs. If a child is still ill and fails to gain weight or improve after two months of treatment, check whether he or she has been given drugs. Never add a single drug to a regimen. This is like using the new drug alone and resistance could develop.

Less commonly, failure to respond to treatment may be because a child has drug resistant TB. If you suspect this, refer the child to a specialist.

Drug resistance

Drug resistance means that certain strains or types of TB bacilli are not killed by the anti-tuberculous drugs given during treatment. Some strains can be resistant to one or more drug. WHO defines a multi-drug resistant (MDR) strain as one that is at least resistant to isoniazid and rifampicin. Someone infected with MDR TB will therefore not be cured by short course chemotherapy which relies on these two drugs.

MDR TB usually occurs in smear positive patients who have previously received two or more courses of treatment. However this situation and, consequently, MDR TB are extremely rare in children.

How drug resistance develops

Drug resistance is caused by inadequate TB treatment and poor TB control programmes. The most common reasons for the development of resistance are:

- incorrect prescription
- irregular supply of drugs
- lack of supervision and follow-up.

There are two types of drug resistance – acquired and primary.

- **Acquired resistance** develops as a result of inadequate treatment. Use of a single drug is the most important cause of acquired resistance. This is because some TB bacilli are naturally resistant to anti-TB drugs. If a single drug is used to treat a patient who is infected with a large number of TB bacilli, only those which are sensitive to that drug are killed, allowing the resistant bacilli to multiply. This is the reason for using several drugs during the initial intensive phase of treatment, until the number of bacilli has been greatly reduced.

- **Primary resistance** occurs when an individual is infected by someone who already has drug resistant TB bacilli. The newly infected person will have TB that is drug resistant from the outset. The number of people with primary resistance – who have drug resistant TB but who have not been treated for TB before – is increasing.

Making sure people with TB take the correct treatment helps prevent the spread of drug-resistant TB.

Although an accurate picture of drug resistance in the world is not currently available because few countries have a reliable drug resistance surveillance system, tuberculosis that is resistant to drugs appears to be increasing in some specific areas and among certain population groups. Resistance varies, for example, in Africa resistance to isoniazid is estimated at between 5 and 10 per cent, but resistance to rifampicin is thought to be low because it has not been widely available. However, resistance to rifampicin has been reported in Thailand.

Drug resistance is most likely to develop in countries with poor TB programmes and uncontrolled prescribing. Where there are good national programmes, MDR TB represents no more than two per cent of all cases of pulmonary TB.

What are the dangers of MDR TB?

MDR TB is much more difficult to treat, even where second-line drugs are available. Treatment of MDR TB can take at least two years and the results are poor. Second-line drugs cost 30-35 times as much as drugs used in SCC treatment of non-resistant TB. Careful precautions are necessary to prevent transmission, especially to health workers caring for MDR TB patients.

HIV and TB in children

Children with HIV are at higher risk of TB infection and of rapid progression to disease than children without HIV. It makes sense to always consider the possibility of TB in a child with HIV infection.

Diagnosis

Diagnosis of TB in children with HIV can be difficult because:

- children who are HIV positive may be tuberculin test negative even when they are infected or ill with TB, because their immune system is not functioning well
- several features are common to both infections. Failure to gain weight, weight loss, intermittent fever, chronic cough, and history of recurrent illness are seen in children with TB and in children with HIV.

Accurate diagnosis is important because:

- children with HIV without TB should not be given TB treatment unnecessarily
- children with HIV and TB need treatment.

Progression and treatment

The natural history of TB in an HIV infected child depends on the stage of HIV disease.

- If the child is still well and the immune system is working properly, the signs of TB will be the same as in a child without HIV infection.
- If HIV is more advanced, TB can spread to other parts of the body and progress to serious illness more rapidly. Disseminated disease, tuberculous meningitis and general enlargement of the lymph nodes are more common in HIV positive children.
- A sick child with HIV and TB will respond well to anti-tuberculosis treatment.
- Children with HIV should **NEVER** be treated for TB with thiacetazone because this drug can cause severe and sometimes fatal side effects in patients with HIV.

Supervision and DOTS

Health workers need to make sure that people with active TB take all their drugs and complete their treatment (treatment adherence). This is especially important during the initial two-month intensive phase of treatment. Parents play an important role in ensuring that children take all their medicines. It may be difficult for parents to get a child to take pills every day for several months. Parents somtimes also stop treatment when the child seems to be getting better. Parents need a careful explanation about the principles of treatment and they need to understand that a child with TB has to complete a course of treatment to be fully cured. A well supervised programme which includes monitoring, reporting and record keeping, training and supervision of staff is also important.

Some programmes hospitalise patients for the initial phase of therapy, if there is no other way to guarantee supervision. But because TB transmission may be greater in overcrowded hospitals and it may be difficult for a mother to stay with a young child in hospital when she has other responsibilities, children should only be hospitalised if there is no alternative. The exception to this is children with severe forms of TB such as tuberculous meningitis and disseminated disease who need to be hospitalised urgently because of the seriousness of their illness and the potential for complications.

Directly Observed Therapy

Ambulatory treatment (when the person is well enough to be at home and takes his or her medication on a daily or intermittent basis) is the recommended approach. But it only works when the person is supervised taking the treatment by a health worker at a clinic or a community health worker during home visits.

This system, called Directly Observed Therapy, Short course (DOTS), is a method to ensure high levels of adherence and completion of TB treatment. DOTS means someone, usually a health worker, takes responsibility for observing the person take each dose of the drugs. The 'supervisor' can be a source of encouragement and support for adult patients and for parents of children taking TB treatment. Parents and supervisors must know how many tablets should be given and how often. If a family member is responsible for giving the child his or her treatment at home, the health worker needs to visit regularly to check that the child is getting the medicine. Directly Observed Therapy is essential during the initial treatment phase – each dose of treatment taken must be observed.

WHO recommends that every country should adopt the DOTS approach, but only where there is a properly functioning TB programme, with trained staff, good record keeping and guaranteed supplies of drugs. Because of poor health services, only about 500,000 of the eight million people who develop TB disease each year have DOTS. Many people are still sent away with a six-month prescription for drugs, and may fail to take the complete course or to make sure that their children do so. This unsupervised approach to treatment not only means people are less likely to be cured, it also contributes to development of drug resistance.

PRACTICAL TIPS

Health workers can help parents make sure their children complete their treatment by:

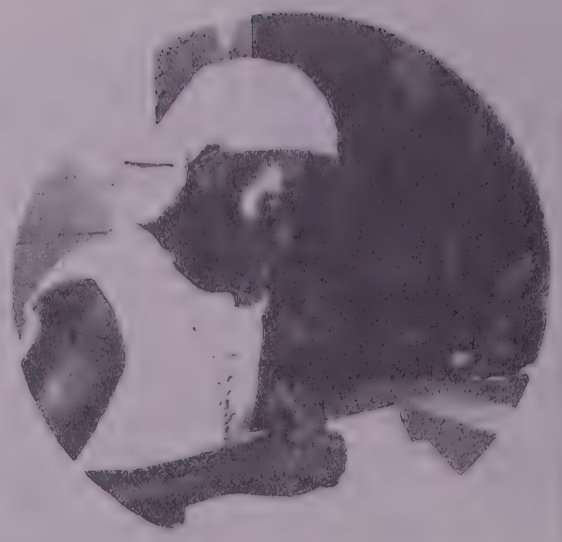
- explaining about TB and common side effects so that parents will not be worried if they occur
- involving all members of the child's family, so that they understand the treatment and make sure the child takes the medicine
- nominating one member of the family to be responsible for the child's treatment
- making written or verbal agreements with the parents about the child's treatment
- providing practical support such as money, food, bus tokens.

SUPERVISION WORKS

In Botswana, TB patients attend the nearest primary health care (PHC) facility for daily supervised treatment. Patients who fail to attend are traced immediately by community health workers, usually family welfare educators, during home visits. High adherence, over 90 per cent, has been achieved through intensive family health education, careful follow- up and integration of treatment and supervision into PHC at the community level.

Cure rates of 75 per cent have been achieved among nomadic people in northern Kenya. Health workers provide temporary housing for people with infectious TB and their families. This makes it possible to supervise their treatment and to check and treat all family members for TB.

Making TB programmes work



ontrol of TB requires a well organised national programme. Delays in referral, the cost of drugs, distance to clinics and negative attitudes of health workers can stop people from seeking treatment for TB symptoms for themselves and their children.

A poor programme is worse than none at all, because of the risk of large numbers of people being given inadequate treatment. This means that they will continue to be infectious to others and can lead to the development of TB strains resistant to available drugs (see page 10).

National TB programmes are responsible for planning, policy, budgets, supervision and training, and should facilitate links between primary, district, regional and national levels.

An effective programme needs:

- a **recording and reporting system** that provides information about case categories and treatment results
- **trained staff** who can screen, diagnose and treat patients, and who understand the principles of supervision
- a reliable smear sputum **microscopy service**, with adequate equipment and trained laboratory personnel
- **treatment services** which provide directly supervised short course chemotherapy
- community and family **education**
- a **reliable supply of drugs and diagnostic materials.**

Health workers should always follow national TB programme guidelines. If there is no functioning national TB programme, WHO TB treatment guidelines should be used.

KEEPING RECORDS

Records are needed for a TB programme to work effectively. The recording system should enable health workers and TB programme staff to plan, monitor and evaluate services and drug supplies and to:

- see how many cases are being detected
- ensure that all potentially infectious cases are being properly screened
- monitor people's progress and adherence to treatment
- make sure everyone is fully treated and assess the effectiveness of treatment
- distinguish new cases from those that have previously received treatment
- prevent the development of drug resistance
- identify problems including where more training or supervision is needed.

For each person, records need to be kept of:

- diagnostic examinations
- treatment
- follow-up results and treatment outcomes.

A record system will usually include the following:

- *child's TB card* (kept by the parents)
- *TB treatment card* (kept at the health facility)
- *clinic TB register* (kept at the health facility)
- *TB laboratory register*
- *district TB register.*

A health worker checks for tuberculin test results as part of a national TB programme

IMPROVED CURE RATE

In 1977, Tanzania established a national TB control programme, fully integrated into the health structure, ensuring reliable drug supplies, training for staff, and using a uniform recording and reporting system. The strong support of the government and donors has helped to avoid problems such as interruption in drug supply. Tanzania's cure rates rose from 43 per cent to nearly 80 per cent in ten years.

Preventing TB transmission in health facilities

Prevention of TB transmission in health facilities is important. Health workers need to be educated about TB and trained in infection control. Good working practices based on the following guidelines can reduce the risk of transmission.

Infants and young children are particularly vulnerable to infection, especially when they are malnourished or have another childhood infection. Children under five who are in hospital because they are sick may be in contact with infectious TB cases. If they have to remain in hospital while their mother is being treated for TB, they are also at risk of infection through close contact with her and others with TB. These children should be given preventive chemotherapy (provided they do not have TB symptoms).

GUIDELINES TO REDUCE TB TRANSMISSION

Let in air and light

- Proper ventilation is one of the most effective measures to reduce TB transmission because it disperses TB germs in the air.
- Ultra Violet (UV) light kills TB germs. Sunlight is a cheap source of UV light. Special UV lights are not recommended because they have not been shown to be effective. They are also expensive, require careful maintenance, and can be harmful if not installed properly.
- Waiting areas, out-patient clinics and patient wards should be well ventilated or aired several times a day, and have large uncurtained windows which allow sunlight in.
- TB wards where doors are closed and windows are open to the outside are ideal.
- Fans are useful for moving air from the wards to the outside.
- In colder climates where the windows need to be closed, air flow from TB wards should not be directed to other parts of the hospital, especially those where there are young children and infants.

Keep infectious TB patients separate

- Remember that the most infectious TB patients are adults with pulmonary disease who are sputum smear positive.
- Keep potentially infectious patients separate from areas where there are young children and infants such as maternal and child health clinics.
- Patients with confirmed smear positive pulmonary TB who have to be hospitalised should be accommodated in separate wards away from patients without TB and especially away from maternity and paediatric wards. This especially important during the initial phase of treatment until they are no longer infectious.
- Infectious adult patients need to understand that they can transmit TB germs to staff, other patients and visitors. Encourage them to cover their mouth and nose when coughing, if possible with a clean cloth or handkerchief. Surgical masks are not very effective, are expensive and can increase stigmatisation of TB patients.

Safe handling of sputum

- Sputum specimens should be collected in a place away from general waiting rooms or hospital wards, in a special receptacle (spittoon) with a lid.
- Laboratories processing sputum specimens should follow guidelines to prevent transmission to laboratory workers.
- Disposable spittoons must be incinerated after use. Metal or plastic spittoons must be disinfected and washed. Anyone handling spittoons should wash their hands afterwards.

Adapted from: Control of tuberculosis transmission in health care settings. Joint Statement of the IUATLD and WHO TB Programme.

Helping communities control tuberculosis

Health workers in the community can play an important role in TB control. They can prevent the spread of infection by educating the community about TB symptoms and how TB is transmitted, and encouraging people with active TB to seek and complete treatment. By checking household contacts of infectious patients, they can identify and manage young children who are at special risk.

Understand local beliefs

Communities need to know about TB symptoms and that it can be treated, and parents need to be aware of when their child needs medical help. Parents' attitudes and beliefs about TB also affect whether or not they bring their children to be checked at a clinic and make sure they complete the treatment.

Studies have found that people may:

- be unaware of TB and its symptoms, how it is spread, and its seriousness
- believe that TB cannot be cured and do not know that with proper treatment people are no longer infectious
- think TB is a disease sent from god, or caused by magic or witchcraft
- think that TB only affects 'cursed' or 'bad' people.

Such beliefs and lack of awareness mean that people may be less likely to seek treatment from modern health services, preferring instead to use traditional healers. They may try to hide TB illness in the family from the rest of the community.

Understanding these attitudes and beliefs could help health workers to give more appropriate advice and to provide more relevant community health education.

Educate about TB

- Explain to people how TB is spread to help counter misbeliefs and stigma.
- Ensure that community members recognise TB symptoms, and understand that it can be cured.
- Encourage people with symptoms to be screened for TB and to seek treatment.
- Advise infectious adults to cover their mouth and nose when coughing or sneezing, and to dispose of sputum carefully.
- Advise families that, if possible, children should not sleep in the same room as an infectious adult.
- Encourage parents to give children their drugs and give practical advice to help them to do this.
- Follow-up to ensure that children are being given their treatment.

Check household contacts

If someone in the house has TB:

- check the whole family for TB, especially young children
- check the nutritional status of the children – those who are malnourished will be particularly at risk.

Ask the parents

- Does the child have fever? How often and since when?
- Has the child lost weight or his or her appetite? For how long?
- Does the child vomit or have headaches?
- Does the child cough or have laboured breathing? How long has he or she had a cough?
- Has the child been given a BCG vaccination?

Examine the child

- Look for clinical signs described on pages 6 and 7.
- Check to see if there is a BCG scar.

Do a tuberculin test

- If the child has symptoms – such as vomiting, fever, a persistent cough and weight loss – he or she should be referred immediately to a doctor.
- If the child has no symptoms but a strongly positive tuberculin test reaction, recent infection is highly likely, and preventive chemotherapy may be needed (see page 5).
- Advise parents to bring a child to a clinic if he or she develops symptoms.

Parents' attitudes affect whether they bring their children to be checked for TB.

Tuberculosis treatment game

One reason why people delay seeking treatment and fail to complete their therapy is the attitude of health workers. Criticising or blaming parents for bringing a child when symptoms are advanced is unlikely to encourage them to come again or to follow instructions about treatment. In Nepal, games have been used to help health workers to think about the way they communicate with members of the community.

The purpose of the tuberculosis treatment game is to help health workers to understand why people stop taking their treatment. The game can be played individually or in groups, with each group playing against the other. It takes about 3 minutes to play.

Procedure

- Before starting the game, describe a typical reaction from a health worker when he or she sees a patient or a parent of a patient who has stopped treatment – often the health worker is angry with the patient.
- Get all the participants to identify reasons why they may have stopped – make an extensive list and then ask the group to identify the 10 most common reasons.
- Draw 10 'stepping stones' on the floor. Leave them blank for the group to write in the reasons. (Some sample reasons are shown in the illustration.)
- Draw a circle about 50cm in diameter on the floor and divide it into six equal wedges and write the numbers one to six in them – draw a boundary line about 2-3m away from the centre of the circle.

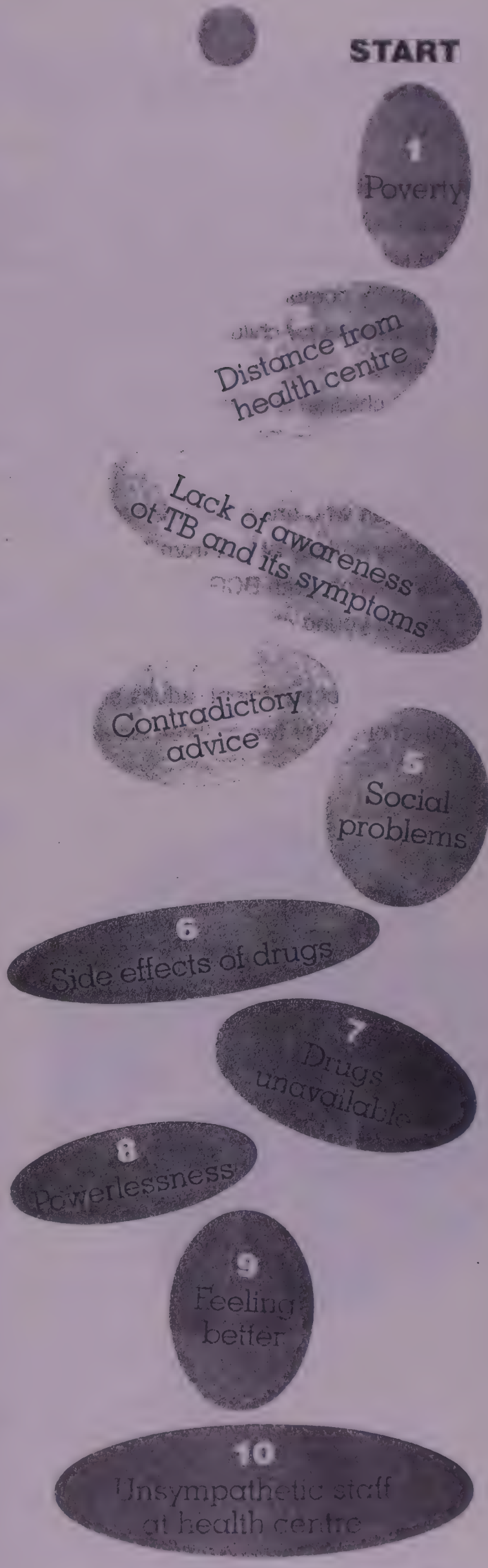
Rules

- The aim of this game is to cross the river using the stepping stones – anyone who slips and falls in has 'defaulted' from treatment.
- Each player takes it in turns to throw a coin (or a stone) into the circle – if the coin lands on a number the player moves that number of stepping stones, if the coin lands outside the circle then the player has fallen off and is out of the game.
- Each player continues until he or she has reached the other side or fallen into the river.

Discuss with the participants

- What proportion fell in? Is this similar to the percentage who default?
- From which stones did most players fall? Are these similar to the reasons why people default from treatment? What are the most common reasons?
- Of the different reasons, for which are patients or parents to blame? For which are health workers to blame? Usually one or two reasons are because of the patient or parents and four or five because of the health worker.
- How can health workers encourage patients with TB or parents of children with TB to ensure that they complete their treatment?

Source: *Smith I*, Tuberculosis control learning games, *Tropical Doctor, July 1993*



Tuberculosis *can* be cured

- Young children and infants living in the same household as an adult with infectious TB are at greatest risk of catching the disease.
- TB kills more women each year than all causes of maternal mortality combined. TB deaths among women have major implications for child survival, economic productivity and family welfare.
- TB in children is difficult to detect and diagnose. If an adult in a household has TB, young children in the family should be checked for TB.
- Children who are malnourished or suffering from another infection are particularly at risk from TB.
- Vaccination (with BCG vaccine) at birth or within a few months can protect young children from the most severe and life-threatening forms of TB.
- With correct treatment, adults and children with TB are no longer infectious after two to three weeks. Almost all can be cured.

Resources

Clinical tuberculosis provides practical information on all aspects of TB control and clinical care. Available for £3.00 in English, French, Spanish and Portuguese from: TALC, PO Box 49, St Albans, Herts, AL1 4AX, UK.

Tuberculosis guide for low-income countries is a handbook providing information for staff involved in primary level prevention and care. Single copies in English, French or Spanish free from IUATLD, 68 Boulevard Saint-Michel, 75006 Paris, France.

Tackling TB and HIV is a new briefing paper (published as issue 31 of *AIDS Action*) from AHRTAG. Available free to readers in developing countries.

Preventing infections in health care settings provides practical guidelines on reducing the risk of blood and air-borne infections. Available free to readers in developing countries and for £5.00 elsewhere, from AHRTAG.

Please write to AHRTAG if you would like a full list of the reference materials used for this supplement on tuberculosis and children.

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MATERIAL ON HIV/AIDS

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The implications of antiretroviral treatments

Informal Consultation
Geneva, 29-30 April 1997

Edited by
Eric van Praag, Susan Fernyak
and Alison Martin Katz

Office of HIV/AIDS and
Sexually Transmitted Diseases

World Health Organization
Geneva

Antiretroviral drugs: classes, modes of action and indications

Current antiretroviral agents for HIV/AIDS can be divided into two major classes of drugs: reverse transcriptase inhibitors (RTIs) and protease inhibitors (PIs). RTIs are further divided into nucleoside (NRTI) and non-nucleoside (NNRTI) subclasses. A third class, integrase inhibitors, is under development. These agents target enzymes which are important for RNA replication and viral functioning. Once the HIV retrovirus has invaded a macrophage or T-lymphocyte, the enzyme HIV *reverse transcriptase* converts the viral RNA genome into a DNA copy, which is then integrated into the host chromosome by the enzyme *integrase*. A third enzyme, *protease*, contributes to viral functioning by catalyzing the cleavage of virion core proteins for final assembly of viable virions. Once HIV has integrated into the host DNA, the virus multiplies rapidly, creating several billion new copies a day. This inevitably results in mutations of the viral genome and the development of variant strains. Some of the mutations may confer resistance to one specific agent or a whole class of ARVs.

Zidovudine (AZT), the first antiretroviral to be developed, became available in 1987. Other NRTIs were introduced in the early 1990s but it took until 1995 to demonstrate that therapy with two drugs was more effective than with zidovudine alone. Monotherapy with AZT is now regarded by many clinicians and researchers as obsolete for the treatment of HIV infection, but is still used for prevention of mother-to-child transmission. The problem of the development of resistance in mothers who have received multiple doses of AZT, in communities where the drug is much used, is not resolved. Bitherapy to prevent MCT is increasingly being used and might become the standard of care in industrialized countries.

Over the last year, evidence has accumulated showing that a combination of three ARVs, including one PI, is the most effective treatment available to suppress the replication of HIV. This is reflected clinically in decreased incidence of OIs, decreased hospitalizations and ability to return to normal functions of daily living. In laboratory tests, it is reflected in decreased viral loads (often to undetectable levels) and increases in the number of CD4 cells. However it is not known how long these benefits will last.

Although combination therapies allow patients to live more normal lives, they require strict adherence to complicated regimens. Some drugs must be taken with meals, others while fasting; some must be taken precisely at six or eight hourly intervals; one of the drugs (ddI) must be taken alone and another requires refrigeration (see Table 6 in the background paper on *Adherence to antiretroviral therapy*). Finally, there is the risk of interactions between ARVs and other drugs commonly used for the treatment of HIV related conditions. Managing these various requirements is time consuming and stressful. In an attempt to solve some of these problems, several new drugs which are more potent, have fewer side effects and easier dosing schedules, which are able to cross the blood-brain barrier and which target the integrase enzyme, are currently being developed and tested.

In 1994, the results of ACTG076, the first study of the use of zidovudine during pregnancy were published and showed that mother-to-child transmission of HIV could be decreased by 67% in HIV-positive pregnant women who were AZT naive and had CD4 counts greater than 200. For the women, the regimen involved oral zidovudine for a median of 11 weeks (range 0-26 weeks) during pregnancy, and IV zidovudine administered during labour and delivery. In addition, the new-born received 6 weeks of zidovudine in drops and was not breastfed.

The promising results of ACTG076 have created a demand for increased access to ARVs for pregnant women worldwide. This has led to additional research which strives to identify shorter, simpler and less expensive ARV regimes to reduce MCT. The details of the current ongoing trials

are provided in the background paper *Antiretrovirals and their role in preventing mother-to-child transmission of HIV 1*. Methods to reduce MCT which do not involve ARVs are also being explored, such as vaginal disinfection, caesarian section rather than vaginal delivery, and formula feeding. Vitamin A and Pokeweed protein are also being investigated as possible MCT preventive agents.

ARVs have also been used for post exposure prophylaxis (PEP). A case control study showed that AZT administered after percutaneous exposure to HIV among health care workers decreased the risk of seroconversion by approximately 79%.

Eleven antiretroviral agents are currently available in different parts of the world. Ten of these agents have been shown to be useful in the treatment of HIV/AIDS by slowing the progression of the disease and prolonging survival.* Table 1 lists the currently available agents, by brand name, class and estimated market cost, based on US pricing in June 1997. (Registration differs from country to country.)

Table 1

Generic Name	Brand Name**	Class	Unit Dose	Cost:Three Months /US$***
didanosine (ddI)	Videx	NRTI	100 mg	420-700
lamivudine (3TC)	Epivir	NRTI	150 mg	690
stavudine (d4T)	Zerit	NRTI	40 mg	700-730
zalcitabine (ddC)	Hivid	NRTI	0.75 mg	630
zidovudine (AZT)	Retrovir	NRTI	100 mg	720-860
indinavir	Crixivan	PI	800 mg	1350
nelfinavir	Viracept	PI	250 mg	1670
ritonavir	Norvir	PI	600 mg	2080
saquinavir	Invirase	PI	600 mg	1720
delvaridine*	Rescriptor	NNRTI	100 mg	
nevirapine	Viramune	NNRTI	100 mg	740

* delvaridine is only available in ongoing clinical trials
** brand names may vary between countries
*** ranges reflect dosing variations

Current standards of care based on published guidelines

Patients usually develop symptomatic HIV disease, and progress to AIDS approximately seven and ten years after infection, respectively. Disease progression can be monitored clinically and with laboratory tests, through viral load measurement and CD4 cell counts. The risk of dying from AIDS is most strongly correlated with a patient's viral load. A patient with a viral load greater than 30,000 copies/mL is 18 times more likely to die than a patient with a viral load less than 500 copies/mL. Although CD4 counts also correlate with disease progression, the association is weaker than with viral loads. A patient with a CD4 count less than 200/cmm is 4 times more likely to die than a patient with a CD4 count greater than 750/cmm. CD4 counts are most useful for making decisions regarding prophylaxis of opportunistic infections (OIs) and for predicting the onset of OIs. (For a general discussion of these issues see background paper on *Treatment of HIV infection:current recommendations for the use of antiretroviral drugs.*)

Guidelines for the use of ARVs have been issued in the last year from groups in several countries. Many crucial questions concerning these therapies, such as when to begin, when to stop, when to change drugs, and which drugs to use have still not been clearly answered from ongoing clinical trials. This is especially so for the treatment of asymptomatic HIV infection (with CD4 greater than 500), where clinical benefit of early treatment has not been proven.

The standard of care for the treatment of HIV infection, at the time of the consultation, was double therapy with two NRTIs or triple therapy with two NRTIs and one PI, or two NRTIs and one NNRTI. It should be noted that data on the use of PIs as initial therapy in early disease is limited. In France, 52% of patients are on a double nucleoside regimen, and 43% are on a triple regimen including one protease inhibitor. In Brazil, bitherapy is recommended for the majority of patients. The most aggressive guidelines treat HIV disease, symptomatic or asymptomatic with CD4 less than 500 and/or viral loads greater than 5-10,000 copies/mL. For asymptomatic patients with CD4 counts greater than 500/cmm, therapy is recommended when the viral load is greater than 30-50,000 copies/mL and should be considered when greater than 5-10,000 copies/mL.

Viral load is monitored every 3-4 months and changes are made in the treatment regime when the viral load increases or the patient no longer tolerates the combination therapy. In addition, complete blood count, liver function tests, amylase and electrolytes are performed every 3-4 months to monitor for adverse reactions. For patients considering initiating ARV treatment, viral load is measured every 6 months.

In current practice, treatment is changed when it fails, when there are adverse reactions, or when drug interactions make its continuation problematic. The proposed virological criterion for treatment failure is viral load greater than 5-10,000 copies/mL or less than 5-10,000 copies/mL, but rising. When PIs are used, it may take 16-20 weeks to reach maximum antiviral effect. "Failure" may be due to several factors, including incomplete suppression of HIV replication, progression of immunological decline, drug interactions, non-adherence, and stimulation of virus replication (due to concurrent viral or bacterial infection).

Unresolved issues

There are conflicting views on the use of ARVs in settings which may not have the resources to perform frequent viral loads or provide bi- and triple therapy. For some, the primary goal is to provide ARVs, whether or not viral load, and/or changes in CD4 cell counts, can be monitored. The treatment may be monotherapy with a NRTI, irrespective of concerns regarding the almost certain development of resistance. This may allow a small increase in survival and quality of life

and perhaps time to "deal" with the disease and die with dignity. Some feel that if any gain in survival or quality of life, no matter how small, is possible, the treatment should be made available to all infected with HIV. This position is unacceptable to those who are concerned about the development of resistance, and consequently the reduced effectiveness of therapy now and in the future.

An alternative suggested at the consultation would be to provide bi- or triple therapy without viral load monitoring to symptomatic patients and patients with AIDS, using clinical signs as a measure of the adequacy of therapy and basic laboratory tests to monitor for toxicity. Some argue that development of clinical signs will most certainly indicate that resistance has already developed, and it will be "too late" to halt this process. Others point out that likewise, once viral load begins to rise, resistance may already have occurred and it is also "too late". This is clearly an area which requires further investigation and discussion in order to reach an agreement that respects both the individual's desire to access treatment and the public health responsibility to minimize the development of resistance.

Post exposure prophylaxis (PEP): guidelines from the US Centers for Disease Control

Guidelines for the use of ARVs to decrease seroconversion following occupational exposure have been developed by the Centers for Disease Control (CDC), based on expert opinion. It should be noted however, that data on the efficacy of ARVs in PEP and on the toxicity of ARVs in non-infected individuals is extremely limited, and that the average risk of seroconversion following percutaneous exposure is very low (0.3%).

For those at highest risk (large volume of blood and/or high titre of HIV in source patient) ZDV, 3TC and indinavir may be recommended; for middle risk, ZDV and 3TC and for lowest risk, ZDV with or without 3TC may be offered. (See MMWR Vol 45, No. 22, June 7 1996, pages 468-472 for complete recommendations.)

In all cases PEP should be initiated 1-2 hours following probable exposure of an HIV-negative health worker and administered for 4 weeks, if tolerated. Health care workers should receive follow-up counselling and medical evaluation, including HIV tests at baseline, 6 weeks, 12 weeks and 6 months. In addition, counselling should include information on the necessary precautions to prevent possible secondary transmission. Adverse reactions should be monitored serologically at baseline and 2 weeks following initiation of therapy.

Issues for the individual

The perspective of people living with HIV/AIDS

For many PLHA, ARVs represent the only hope and the best available treatment, which while not life saving, may increase survival and quality of life. A chronic illness requiring mostly outpatient care is a very different prospect from a disease which - once it develops - causes much suffering and is rapidly fatal (6 months to 2 years). Understandably, for PLHA, obtaining these drugs is an imperative.

For the majority of PLHA, the difficult regimen and unpleasant side effects are aspects which must be tolerated in order to reap the benefits of the treatment. It is increasingly recognized that clinicians and other health providers, as well as the PLHA him or herself, have responsibilities in facilitating adherence. For some PLHA, unpleasant side effects may be severe enough for them to decide to stop treatment.

Quality of life on ARVs can best be assessed by the individual under treatment. Assessments may vary considerably as people react very differently to discomfort, stress and inconvenience. For asymptomatic PLHA, the decision is particularly difficult, as they may be leading completely 'healthy' lives. Introducing ARVs may transform a healthy life into one which is dominated by the effort required to manage a complicated regimen and made less agreeable by unpleasant side effects.

Obtaining ARVs "whatever the cost" is likely to be the major preoccupation of many PLHA who are aware that the treatment exists and is being provided at no or little cost to all PLHA in industrialized and some middle income countries. Governments are sometimes seen as having an obligation to provide ARVs by whatever means to all those in need. Whilst policy makers must weigh this option against other more cost effective interventions which address public health priorities in general, it would be inappropriate and unrealistic to expect PLHA to do so.

Past experience shows that drug prices do come down; the people concerned often have to lobby and fight, ask for help, and demand that their rights to treatment be respected. Many PLHA and those working with them feel that providing ARVs is a question of political will. They point out that HIV/AIDS activists have already set precedents in the past in challenging established procedures regarding access to treatment, and are likely to do so again in relation to the new therapies.

Risks and benefits of treatment

For the individual patient, the decision to begin ARV treatment requires careful consideration of a number of issues and thorough discussion with his or her physician. Benefits of therapy may include:

- a longer life
- control of viral replication
- development of fewer drug resistant mutations, particularly when adherent to triple therapy
- prevention of immune deficiency
- delayed clinical progression of disease, fewer opportunistic infections
- decreased risk of transmission.

Potential disadvantages include:

- impairment of quality of life because of the difficult regimen or unpleasant side effects.
- early development of drug resistance and cross resistance, when ARVs are not effective, limiting the number of available therapeutic options in the future, and increasing the risk of transmission of resistant strains.
- raising false hopes of therapeutic gain in a proportion of patients who will either not respond or not tolerate the therapies.

Adverse reactions to ARVs and interactions between ARVs and other drugs commonly used to treat HIV-related illnesses are listed in Table 2. It should be noted that long term toxicities, particularly with respect to children who have received AZT *in utero* and post-natally are not known. Of particular concern are interactions with drugs for concurrent TB infection. Patients on rifampin or rifabutin for the treatment of TB, in general, should not continue or begin treatment with PIs (see background paper on *Adherence to Antiretroviral Therapy* for treatment options).

Table 2*

Drug	Adverse reactions	Drug-drug interactions
delvaridine	rash, abnormal LFTs	rifampicin, rifabutin, ddI, antacids, anti-epileptics, PIs
didanosine (ddI)	pancreatitis, peripheral neuropathy, nausea/vomiting, diarrhoea	fluroquinolones, dapsone, isoniazid, itraconazole, ketoconazole, tetracyclines
indinavir	hyperbilirubinemia, nephrolithiasis	rifabutin, rifampicin, cisapride, terfenadine, astemizole, warfarin
lamivudine (3TC)	nausea/vomiting, pancreatitis	
nelfinavir	diarrhoea	
nevirapine	rash, Stevens-Johnson syndrome, abnormal LFTs**	PIs, rifabutin, rifampicin, indinavir
ritonavir	nausea/vomiting, diarrhoea, hypertriglyceridemia, abnormal LFTs, peripheral neuropathy, perioral paraesthesia, headache	alprazolam, clarithromycin, diazepam, erythromycin, ketaconazole, itraconazole, rifabutin, saquinavir, tricyclic antidepressants, oral contraceptives
saquinavir	severe hepatic impairment, diarrhoea, nausea, abdominal pain	ketoconazole, rifampicin, rifabutin, phenytoin, carbamazepin
stavudine (d4T)	peripheral neuropathy, pancreatitis, anemia, neutropenia, headache, nausea	
zalcitabine (ddC)	peripheral neuropathy, pancreatitis, stomatitis	warfarin
zidovudine (AZT, ZDV)	anemia, neutropenia, headache nausea	

* NOTE: This table is not exhaustive.
** Liver Function Tests

Resistance

The rapid replication rate of the HIV virus, coupled with the many errors made by HIV's reverse transcriptase enzyme in copying the HIV genome, produces many mutations of the HIV virus. These mutations may result in changes in the protease and reverse transcriptase enzymes, so they are no longer inhibited by ARV agents. In the presence of antiretroviral agents, these variants may be amplified, resulting in drug resistant strains. In vitro studies suggest that resistance to zidovudine develops in approximately six months, although clinical evidence of resistance may take up to two years to appear. Resistant strains emerge at varying rates with other NRTIs. However, resistance to NNRTIs and PIs can develop over the course of weeks if they are used intermittently or as monotherapy. A recent, small study observed rapid rises in HIV RNA after a few days of missed doses of saquinavir taken as monotherapy and a possible association with the emergence of resistant strains. Within the class of PIs, there is often cross-resistance between different compounds. (See background paper on *Resistance to antiretroviral drugs* for further details on this subject)

When AZT is used as monotherapy, evidence suggests that HIV drug resistance is probably causally associated with treatment failure and death. When a patient is able to adhere to the rigorous schedule needed to take triple therapies, viral replication may be suppressed, limiting the opportunity for the virus to develop resistant strains. Unfortunately, clinical practice suggests that this may only be achievable in a proportion of patients. In addition, there are strong theoretical reasons to expect that sub-optimal serum concentrations of ARVs, due to poor adherence, drug-drug interactions or viral stimulation, will lead to a more rapid development of resistance. Data on this issue are expected to be published soon.

Although drug resistance will develop in those individuals who are on AZT monotherapy for six months to two years, resistance is less likely to develop when it is used for shorter periods of time to decrease mother-to-child transmission of the virus. Consultation participants suggested that in order to maintain the effectiveness of zidovudine monotherapy in decreasing mother-to-child transmission of the virus in a particular community:

- women should receive short course monotherapy with zidovudine during the perinatal period;
- between pregnancies women should be offered bi- or triple ARV therapy or no therapy - monotherapy is not an option;
- monotherapy should be discouraged in the community at large, to reduce the likelihood that zidovudine resistant strains of HIV will be transmitted to women of child-bearing age.

These standards are crucial for limiting the emergence of drug resistance. If ARVs are not used responsibly, women will acquire AZT resistant virus and transmit it to their children and partners. This limits future treatment options for all members of the community. In addition, the issue of viral rebound in women who stop AZT following pregnancy has not been adequately addressed for many settings. It was suggested, although there are no data to support it, that women may risk accelerating their own disease progression when taking ARVs as monotherapy to reduce MCT, for limited periods during several pregnancies.

Adherence

Given the complicated dosing schedules for antiretroviral agents, the constant threat of the development of resistance and the immense cost of the therapies, adherence to the regimen is essential. In general, adherence to medical regimens is poor, with published literature suggesting

rates as low as 50% for treatment of many diseases. There is little data on adherence in HIV disease, and virtually no data on adherence with respect to bi- and triple therapy combinations of ARVs. One careful prospective study of adherence to zidovudine monotherapy, outside of a trial setting, reported that only 26% of patients were correctly using their medications at six months. Anecdotal reports are not useful as most clinicians assume a high rate of adherence in their patients, which is not borne out by studies in which patients are directly questioned.

Despite these sobering statistics, there are ways in which patient adherence can be improved. A key factor is the patient-clinician relationship. The decision to begin ARVs should be approached openly by the clinician and the drugs should be offered equally to all patients. Treatment decisions should be made jointly between the patient and the clinician after careful discussion of the pros and cons of treatment, treatment options, possible adverse reactions, necessity for adherence and the long term emotional (and often financial) commitment that one must make to successfully use ARVs. This is clearly very difficult in many clinical settings where clinicians often have only a few minutes to spend with each patient.

When the decision has been taken by the patient and clinician to start ARVs, additional psychosocial support to help maintain adherence to the regimen, needs to be organized. This may include material support organized by social services, NGOs or community groups, counselling, emotional support from partner(s), family, and friends - as well as easy and confidential access to a clinical setting and care provider to deal with any concerns and for routine follow-up. In many settings, this level of care and social support is not yet developed.

In the development of new drugs, issues which make adherence easier should be addressed, such as minimal adverse reactions to the medication, fewer drugs and tablets each day, less frequent dosings, and little disruption to one's lifestyle.

Conclusions

The informal nature of the consultation with its array of varying viewpoints, while facilitating important points of consensus, allowed real concerns and differences to surface.

There was a shared understanding that these drugs can improve the life prospects of PLHA and that triple therapy represents the best treatment option available currently. However, the vast majority of those living with HIV/AIDS are unable to access these treatments which are extremely expensive, difficult to adhere to, and require efficiently functioning health and social services.

The consultation recognized the primacy of the need to respond to the individual suffering of PLHA while acknowledging concerns about long term sustainability and safety of ARVs, and responsibilities for the health needs of the general population. Two distinct approaches to providing ARVs emerged during the consultation. One requires that ARVs be provided only when appropriate health and social support systems are in place, while the other supports the provision of ARVs in order to "force" health systems to follow with adequate services.

The consultation reached consensus on a number of **guiding principles**:

- Universal access to care and treatment, a principle which WHO promotes as a human right, is the ultimate aim. The fact that access might not be achieved immediately and universally does not preclude progressive introduction of ARVs, recognising that they are already present in countries. The stark contrast between industrialized countries where patients are usually receiving these treatments through public and private insurance schemes and developing countries where the majority of those requiring treatment cannot access these drugs, is ethically unacceptable.

- As an overarching ethical principle, it must be recognized that triple ARV therapy currently represents the most advanced therapy of choice for people living with HIV/AIDS. There is therefore an obligation for governments to make every effort to increase access to these treatments within the context of national health programmes which address competing health care needs. Governments must ensure non-discrimination and equity in access among PLHA and among those living with other life-threatening conditions requiring comparably costly and complex therapies.

- The provision of ARVs must not divert resources from HIV prevention activities (e.g., control of STDs, promotion of safer sex including condoms, and ensuring a safe blood supply), the treatment of opportunistic infections, and research to develop preventive tools, particularly vaccines and microbicides. Neither should it divert resources from other essential public health programmes.

- ARV treatments must be supported by a functioning health and social system which ensures adequate diagnosis and treatment of opportunistic infections, appropriate pain management, and correct use of and adherence to ARVs to avoid the emergence of drug resistance and transmission of resistant strains.

- Adherence is a required component of effective treatment, not a precondition for access to treatment. Patients should not be excluded *a priori* from ARV treatment because they belong to groups regarded as unlikely to adhere (e.g. injecting drug users, the homeless and the poor). Health providers' roles and responsibilities in ensuring adherence must also be recognized. The assessment of whether the treatment can be properly adhered to, and the decision to start or to continue treatment should be made jointly by the clinician and the patient. Adherence needs to

be nurtured and supported, without violating confidentiality, through a team approach involving nurse, physician, social worker and family.

- The supply, distribution and provision of ARVs require national quality assurance systems to be in place. Governments have a regulatory and supervisory role in these areas and in addition, responsibility for issues such as price regulation, customs and other taxes, quality control, and the monitoring of safety and resistance.

- Cost is a major issue. Collaboration between and within countries to enable those who are most in need to obtain treatment, should be promoted and mechanisms/strategies put in place to effect such solidarity. It is ever more urgent for governments to reconsider the level of the health budget in relation to the budget for other sectors.

- Commitment to continue basic science research into drugs and research on clinical outcomes is essential as none of the currently available ARVs are ideal and a number of promising drugs are under development. In addition, treatment standards and recommendations need to be updated regularly to take into account new data on outcomes and newly registered products.

- The pharmaceutical industry is a key partner in health care, and has social responsibilities as do all civil organizational and institutional bodies. Their collaboration is essential. Continued negotiations involving industry, UN agencies, donors and governments on bulk and preferential prices, on innovative mechanisms, good manufacturing practices, and research priorities is crucial for promoting access to effective ARV therapy.

- Prevention and care are two sides of the same coin. All prevention efforts reduce or limit the final number of infected people needing care. Whenever care is provided, there is a golden opportunity to provide or reinforce prevention education.

The consultation reached agreement on a number of **recommendations**:

- Long term affordability based on scenarios which assume full coverage and total adherence is not achievable at present in most countries. A useful approach might be to ensure access at limited centres of excellence where clinical, laboratory and social support can be guaranteed. Allocating different therapies to subsets of people with HIV-related conditions, taking into account the realities of different settings, may represent a rational strategy offering affordable starting points: prevention of mother-child transmission; post exposure prophylaxis for health workers; treatment of AIDS patients, symptomatic HIV-infected patients and finally asymptomatic HIV-infected patients. Consensus-oriented meetings involving all stakeholders at country level could examine these types of allocations for various settings.

- Because of the high daily turnover of virus production, resistant strains develop very easily. Strict adherence to the drug regimen is therefore essential. ARV combination therapies are not as yet "user friendly" and in conditions of limited support, this frequently leads to intermittent and irregular use. Emergence of resistance should be carefully monitored through a network of collaborating laboratories. WHO/UNAIDS could establish such a coordination mechanism.

- In order to minimize unregulated supply and distribution leading to irregular provision, unsupervised use and the emergence of resistance, there need to be effective national drug regulatory authorities.

- The prevention, diagnosis and treatment of opportunistic infections remains an essential component of the clinical management of HIV/AIDS patients. Following WHO's criteria for

selection of essential drugs, governments need to consider adding drugs for opportunistic infections, other HIV-related conditions and pain management to Essential Drugs Lists.

- International technical agencies and programmes should collect and widely disseminate information on all aspects of ARV treatments including the drugs themselves, rational approaches to problems of adherence and resistance, prescription guidelines, health system requirements, pricing policies and financing options.

- Clinical studies in all countries should follow a basic set of ethical guidelines. All clinical studies should aim to provide meaningful estimates of the gain in quality-adjusted life years, reflecting not only changes in survival but also improvements in the quality of life.

- The currently available nucleic acid amplification assays (DNA and RNA) used to measure viral load are not equally sensitive and/or equally efficient in amplifying all known HIV subtypes. Most RNA assays have been optimized using HIV-1 subtype B, found in industrialized countries. The tests need to be improved to allow accurate detection of the HIV variants most prevalent in Africa, Latin America and Asia. The standardization of these assays is also an urgent priority.

- Viral load measurement is highly desirable to monitor efficacy of ARV treatments in asymptomatic patients.

- Operational research on how best to implement ARV treatments in settings where resources are limited and adherence beset with difficulties, is needed in low and middle income settings.

- Training of health professionals in the correct use of ARVs is essential if the decision to introduce them is made. Clinical guidelines should be developed for professional use. Training should be undertaken to reach all care providers as a team.

Given the broad scope of discussions and the divergent views expressed, it was agreed that many questions/issues could not be answered in the context of this consultation. **Remaining questions/issues** were:

- Do the currently available ARVs justify substantial commitment of public funds? Would it be more rational at this time to wait for the development of drugs for the treatment of HIV infection which are cheaper and easier to take?

- What is the comparative efficacy of different antiretroviral regimens in terms of extending survival and improving the quality of life for people living with HIV/AIDS?

- Is viral load measurement a requirement for triple and double therapy in both asymptomatic and symptomatic patients?

- Should ARVs be included in Essential Drugs Lists?

- Should monotherapy be considered obsolete for treatment of HIV/AIDS and recommended only for reduction of mother-to-child transmission? If it is the only drug available to PLHA, should treatment be withheld?

- If reduced infectivity with new ARV treatments were conclusively demonstrated, might the consensus on voluntary consent for testing and treatment be weakened? Might there be a call for mandatory testing to identify and treat HIV-infected people in order to prevent transmission?

- As regards equity of access, much attention has been paid to the issue of distributive justice once the price has been fixed, but little attention has been paid to the ethics of pricing itself. Are current market prices fair or just?

ARV treatments are fraught with **difficulties** many of which are only starting to be identified and assessed - let alone resolved.

- Quality of life has to be carefully considered. Prolonging life and reducing opportunistic infections are measurable improvements. Unpleasant side effects, a very complicated regimen, and the sheer stress of attempting to adhere to this and simultaneously live a fuller life, are just some of the factors which together affect quality of life. Added to this, in some poor settings, is the weight of responsibility of devoting all personal resources and those of the extended family, to these medications. For patients who are asymptomatic, the adverse effects and disruptions to daily life associated with ARVs may actually introduce the first unpleasant effects of HIV infection into their lives.

- The development of resistance is always "just around the corner". It has been shown that minor lapses in adherence may lead to the development of resistance and thus interfere with efficacy. The question has to be posed whether avoiding the risk of transmission of resistant strains is not more important in the long term than allowing patients known to have difficulties in adherence to start or continue therapy.

- It is almost certain that given a treatment which is perceived as life saving, but that is prohibitively expensive and hard to obtain, a black market will form; counterfeit drugs will start to circulate and a parallel drug supply system will operate. In this situation, everyone loses out. Patients may buy ineffective products; whilst those receiving quality drugs may use them without medical supervision, increasing the likelihood that resistant strains will develop and spread.

In terms of **minimum requirements** for the safe and effective use of ARVs, the consultation agreed on the following:

- Availability of reliable, inexpensive tests to diagnose HIV infection and access to voluntary and confidential counselling and testing.

- Adequate management of opportunistic infections including availability of affordable drugs for their treatment and prophylaxis.

- Laboratory facilities with the capacity to run liver function tests, blood count and electrolytes, to monitor for adverse reactions.

- Appropriate training for clinicians and nurses in the correct use of ARVs.

- Support of a social network to help patients adhere to the regimen.

- Strengthening of health and social services in a continuum of care, from the home, through community health centres, district hospitals to referral centres, with flexible and timely referral and coordination procedures; provision of material and psychosocial support for those taking ARVs at various levels of the continuum.

- Reliable, long-term and regular supply of drugs for palliative care and opportunistic infections at the health centre level.

- Joint decision making between physician and patient on all aspects of ARV treatment, including the decision to begin ARVs.

This consultation is the beginning of a process of broadening access to ARVs and any future promising treatments for HIV/AIDS, for all who need them. The process must advance stepwise in conjunction with new discoveries in basic science, clinical and operational research in different settings, the needs and legitimate demands of PLHA, improvements in health and social support services, and evolving government priorities.

The **next steps**, for WHO in collaboration with UNAIDS in follow up to the consultation will be:

- In response to urgent government requests, technical and policy guidelines on specific issues to be prepared and regularly updated.

- Follow-up technical meetings which will aim to reach consensus on selected key issues.

- A meeting with representatives of the pharmaceutical industry to develop strategies to improve access to HIV-related drugs in low and middle income countries was organized by UNAIDS in June.

- A meeting to review the joint UN strategy on access to drugs for HIV/AIDS and related illnesses based on the collective experiences of WHO, UNICEF, UNDP, UNESCO and the World Bank was called by UNAIDS at the end of June.

All who participated in this consultation explored difficult issues in depth, widened horizons - and learned much in the process. WHO and UNAIDS count on all participants to carry on this reflection in their daily work and to feed back to us and to all the people with whom they work, their insights and eventual conclusions. As one of our participants, a person living with HIV/AIDS said, as she closed the consultation, "This is not an overnight process. Let us build slowly. Each day and each month, more people will have access to ARVs. Let us take it a step at a time, a day at a time - the way I live my life".

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Longitudinal evaluation of severely anemic children in Kenya: the effect of transfusion on mortality and hematologic recovery

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Objective: To determine the effect of transfusion on hematologic recovery and mortality among severely anemic children during and after hospitalization in rural Kenya.

Design: Prospective cohort.

Methods: We collected clinical and laboratory information on all severely anemic children (hemoglobin < 5.0 g/dl) and a 33% sample of children with hemoglobin ≥ 5.0 g/dl who were admitted to the pediatric ward of a rural Kenyan hospital during a 6 month study period. Children were followed during hospitalization and at 4 and 8 weeks after admission.

Results: Overall, 303 (25%) of the 1223 hospitalized children had hemoglobin < 5.0 g/dl, 30% of whom died during the study period. Severely anemic children who were transfused had a higher mean hemoglobin level at discharge (9.0 g/dl) than non-transfused children (5.8 g/dl, $P < 0.001$) and maintained a higher mean hemoglobin during the 8-week follow-up period. However, the presence of malaria parasitemia on follow-up negated the benefit of transfusion on hematologic recovery at both 4- and 8-week visits (longitudinal linear model, least square means, $P > 0.05$). Transfusion was associated with improved survival among children with respiratory distress who received transfusions within the first 2 days of hospitalization.

Conclusions: The use of transfusion can be improved by targeting use of blood to severely anemic children with cardiorespiratory compromise, improving immediate availability of blood, and treating severely anemic children with effective antimalarial therapy.

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Introduction

Over a decade after the development of a screening test for HIV, the reduction of the transmission of HIV by blood transfusion in sub-Saharan Africa remains a public health challenge. Screening of blood has been difficult in many African countries due to lack of resources for the purchase and distribution of equipment,

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reagents and the technical training required for an effective blood screening program [1,2]. In a survey of 733 hospitals in Zaire, only 29% received HIV testing kits on a regular basis and few centres had standard practices of the recording of HIV test results [3]. One year after implementation of blood donor screening, an estimated 25% of pediatric HIV infections were still caused by blood transfusions [4]. Even in areas that are able to screen blood, the rate of new infections in many African countries is high and HIV screening tests are unable to detect recently-infected blood donors who have not yet developed HIV antibodies [5,6].

Confronted with the continuing problems of blood safety in developing countries, the reduction of unnecessary transfusions has been emphasized as a practical and cost-effective method to reduce transfusion-associated HIV transmission [1,2,7–9]. This strategy is particularly important among children, who receive 50–67% of all transfusions given in many African countries [10–15]. In Tanzania, an audit of transfusion practices found that 75% of all avoidable transfusions were among children under 5 years of age [16]. Studies in Kenya and Côte d'Ivoire demonstrated that nearly half of the pediatric transfusions could have been prevented without increasing in-hospital mortality if transfusions had been limited to children with severe anemia (hemoglobin less than 5.0 g/dl in Kenya and less than 6.0 g/dl in Côte d'Ivoire) who demonstrated clinical evidence of cardiorespiratory decompensation [17,18]. However, these studies evaluated only in-hospital survival, and did not account for variations in the length of hospitalization, the effects of other underlying illnesses, and the risk of recurrent anemia and anemia-associated mortality after the period of hospitalization. We conducted this study in a malaria-endemic area of Kenya to evaluate the effect of transfusion on pediatric mortality and hematologic recovery both during and after hospitalization.

Materials and methods

Patients

The study was conducted as part of a series of studies on anemia, malaria, and child mortality at Siaya District Hospital (SDH), located in a rural area of western Kenya with intense, perennial transmission of *Plasmodium falciparum* malaria. Although 75% of *P. falciparum* infections in this area exhibit moderate to high levels of resistance (RII or RIII) to chloroquine therapy [19], chloroquine was often used as standard treatment for children with malaria.

All children who were admitted to the 50-bed pediatric ward from March to September 1991 had their hemoglobin measured by the study team at the time of admission. Each child with severe anemia (hemoglo < 5.0 g/dl) was enrolled, along with the next c admitted with hemoglobin ≥ 5.0 g/dl (constituti 33% sample of children with hemoglobin ≥ 5.0 g/dl

At the time of enrollment, medical history an venous blood sample were collected and a standard physical examination was performed. Signs cardiorespiratory compromise were recorded. For purpose of analysis, 'respiratory distress' was define having intercostal or subcostal retractions, forced ex ration (grunting), or nasal flaring. These were selec as clinical indicators for the need for increased oxyg carrying capacity that could be recognized in ar where diagnostic equipment may not be availab Young children frequently had tachypnea or tachyc dia associated with fever or dehydration; these sig were not included as indicators of cardiopulmona compromise due to their poor specificity. Diagno were assigned by the principal investigators accordi to standardized criteria.

Children were evaluated daily during hospitalizati and a capillary blood sample was collected at discharg Patients were requested to return for follow-up weeks and 8 weeks after the date of their admissio when a medical history and capillary blood samp were collected. Patients were visited at their homes they did not return for their scheduled follow-up. children died between follow-up visits, the report date of death was recorded. To standardize follow-u periods for the purpose of analysis, '4-week follow-u included any visits between 15 and 45 days after th date of admission, and '8-week follow-up' applied any visits more than 45 days after admission.

During hospitalization, all medical care, including th use of blood transfusion, was administered by hospit staff according to routine hospital practice. Whol blood, screened for HIV by the hospital blood bank was used for transfusion. Hospital staff reported tha they transfused children with hemoglobin < 5.0 g/d However, transfusions that were ordered were ofte delayed for days or not administered because blood o other supplies were not available.

Laboratory

Capillary hemoglobin was measured at the time o admission, discharge, and follow-up (HemoCue, Inc Mission Viejo, California, USA). At enrollment, venous blood sample was collected for complete bloo count (Coulter Counter, Model M350; Coulte Electronics, Luton, Bedfordshire, UK), blood culture and a thick and thin blood smear for malaria parasites Malaria smears were stained and read by study team technicians. Serum was tested for HIV-1 by enzyme linked immunosorbent assay (Wellcozyme, Murex Diagnostics, Dartford, Kent, UK), and repeatedly reac

tive specimens were tested by Western blot. Cerebral spinal fluid was cultured from children with mental status changes (coma, lethargy, hypotonia or non-consolable irritability). Children with tachypnea, grunting, nasal flaring, intercostal retractions or wheezing received a chest roentgenogram.

Statistical analysis

Chi-square and Wilcoxon rank sum tests were used to evaluate variables associated with anemia and mortality among severely anemic children who were and were not transfused. To evaluate the effect of transfusion on mortality, we computed Kaplan–Meier estimates of the survival functions for severely anemic children, stratified by the presence of respiratory distress (grunting, flaring, or nasal retractions) and receipt of transfusion. Proportional hazards models were constructed to quantify the association between transfusion and survival, while controlling for hemoglobin, malaria parasitemia, respiratory distress, concomitant illnesses, and medical therapy. To evaluate the effect of transfusion on mortality according to underlying illness, interaction terms were assessed for each diagnosis with transfusion. Backwards elimination was used to eliminate variables that were neither confounders nor associated with mortality. The effectiveness of transfusion in reducing mortality was defined as $1 - HR$, where HR is the hazard ratio for transfusion obtained from the proportional hazards model. The effectiveness can be interpreted as the percentage reduction in mortality obtained from transfusion.

To evaluate the effect of transfusion on hematologic recovery, we constructed a weighted longitudinal linear model of hemoglobin at each follow-up for all of the hospitalized children (PROC MIXED, SAS version 6.08, SAS, Cary, North Carolina, USA), according to receipt of transfusion, mortality, and malaria parasitemia on admission and follow-ups, while controlling for other factors associated with hemoglobin (e.g., age, underlying illness). The modelled hemoglobins for children who ultimately died were fitted with interaction terms, when significant, to allow for changes in hemoglobin that were different from children who survived throughout the follow-up period. This methodology generalized existing linear modelling techniques by allowing the user to specify the nature of the correlation between observations (in this case, patient follow-ups). Previous methodologies either forced an assumption of independence between patient visits or were quite limited in the types of correlational structures that could be assumed. Our models assumed an autoregressive (lag 1) correlation between successive patient visits. The final model and correlational structure were deemed acceptable, based on the close fit of the estimated least squares means to the observed cell means.

Results

Study population

A total of 1223 children were admitted to the pediatric ward during the study period. Of these, 303 (25%) had hemoglobin < 5.0 g/dl and were enrolled in the study, along with 303 with hemoglobin ≥ 5.0 g/dl. Ninety-six per cent of the children enrolled were under 5 years of age. All enrolled patients were monitored for the 8-week follow-up period except for 15 (5%) who had moved and could not be located after discharge.

Severe pediatric anemia

Children with hemoglobin < 5.0 g/dl were younger and more likely to have malaria parasitemia and clinical signs of respiratory compromise compared with children with hemoglobin ≥ 5.0 g/dl. Children with hemoglobin < 5.0 g/dl were admitted for various illnesses, but no admission diagnoses were significantly associated with severe anemia (Table 1).

Table 1. Characteristics of patients less than 5 years of age with hemoglobin levels at admission < 5.0 g/dl and ≥ 5.0 g/dl who were and were not transfused. Siaya District Hospital, March-September, 1991.

	Hb < 5.0 g/dl				Hb ≥ 5.0 g/dl	
	Total (n=303)	Transfused (n=187)	Not transfused (n=116)	P*	Total (n=303)	P†
Mean age ± SD (months)	12.3 ± 16.6	12.7 ± 18.3	11.7 ± 13.3	NS	16.4 ± 19.3	< 0.01
Male sex (%)	50.2	46.6	52.4	NS	50.0	NS
Mean Hb	3.5 ± 0.9	3.4 ± 0.9	3.7 ± 0.9	< 0.01	8.8	< 0.0001
Malaria parasitemia on admission (%)	84.5	84.8	84.1	NS	63.7	< 0.0001
Diagnosis‡						
Malaria (%)	32.6	32.1	31.9	NS	25.7	NS
Malnutrition (%)	22.3	24.0	19.6	NS	24.0	NS
Enteritis (%)	13.9	12.3	16.4	NS	23.4	< 0.01
Bacteremia (%)	12.2	11.2	13.8	NS	11.9	NS
Pneumonia (%)	7.3	8.6	5.2	NS	6.9	NS
HIV Seropositive (%)	7.6	8.0	6.9	NS	9.2	NS
Respiratory distress (%)	63.4	72.2	49.1	< 0.001	41.6	< 0.0001
8-week mortality rate (%)	30.0	21.4	41.4	< 0.001	19.5	< 0.01

*Transfused versus not transfused. †Hb < 5.0 g/dl versus Hb ≥ 5.0 g/dl. ‡Patients may have more than one diagnosis. Hb, Hemoglobin; SD, standard deviation.

Table 2. Mean hemoglobin of severely anemic children who were and were not transfused.

	Number living	Number died (%)*	Number missing	Mean Hb ± SD g/dl	P†
Admission					
Transfused	187	–	–	3.4 ± 0.9	< 0.01
Not transfused	116	–	–	3.7 ± 0.9	
Discharge‡					
Transfused	163	15 (8.0)	9	9.0 ± 2.8	< 0.0001
Not transfused	62	32 (27.6)	22	5.8 ± 1.1	
4-week follow-up					
Transfused	148	18 (9.6)	6	9.2 ± 2.5	< 0.001
Not transfused	62	12 (10.3)	10	7.8 ± 2.5	
8-weeks follow-up					
Transfused	140	7 (3.7)	7	8.9 ± 2.6	< 0.001
Not transfused	60	4 (3.4)	8	7.5 ± 2.4	

*Number of children who died/total number transfused or not transfused. †Wilcoxon rank sum test, mean Hb levels of children transf versus not transfused. ‡Hb level at discharge was not available for 31 (10%) of the severely anemic children who left the hospital b discharge, without notification of hospital staff. Hb, Hemoglobin.

Transfusion, malaria parasitemia, and hematologic recovery

Although hospital staff reported that they ordered transfusions for children with hemoglobin < 5.0 g/dl, 116 (38%) of these children were not transfused, most often due to shortages of blood and supplies. Characteristics of children with hemoglobin < 5.0 g/dl who were and were not transfused are summarized in Table 1. In addition, transfusions were often delayed; 34% of the transfused children received their blood 2 or more days after the transfusion was ordered.

Transfusion significantly increased the mean hemoglobin level. Among the 229 severely anemic children who were living at the time of discharge, the mean hemoglobin level at discharge of the transfused children (9.0 g/dl) was significantly higher than that of the children who were not transfused (5.8 g/dl, Wilcoxon rank sum test, $P < 0.001$). Although mean hemoglobin continued to rise after discharge in both the transfused and non-transfused groups, transfused children continued to have significantly higher mean hemoglobin levels at both the 4-week and 8-week follow-up visits compared with those who had not been transfused (Table 2).

Among the severely anemic children, hematologic recovery was significantly attenuated by the presence of malaria parasitemia at the time of follow-up, in both the transfused and non-transfused groups. For children without parasitemia on follow-up, the longitudinal models of all pediatric admissions demonstrated that transfused children continued to have significan higher mean hemoglobin levels at both the 4-week 8-week follow-up visits compared with those who not been transfused (least-square means of hemoglo at 4 weeks: 10.2 ± 0.21 versus 9.6 ± 0.15 g/ $P = 0.01$; at 8 weeks: 10.7 ± 0.27 versus 9.8 ± 0 g/dl, $P < 0.01$). However, the presence of malaria p asitemia at the time of follow-up negated the benefit transfusion on hematologic recovery. Among childr with parasitemia, on follow-up, there was no significa difference between the mean hemoglobin levels those who were transfused and those not transfused a weeks (8.8 ± 0.23 versus 8.9 ± 0.19 g/dl) and 8 wee after admission (8.4 ± 0.22 versus 8.3 ± 0.18 g/dl). T same relationship between parasitemia and hematolog recovery was seen among children who survived died during the study period (Table 3).

Transfusion and mortality

Of the 288 severely anemic children who complete the 8-week study, 30% (88) died: 16% (47) died durin hospitalization, 10% (30) died between the time of dis charge and the 4-week follow-up, and 4% (11) die between the 4- and 8-week follow-up visits. Childre with severe anemia were significantly more likely t die during the study period than those with hemoglo bin ≥ 5.0 g/dl (30% versus 19%, χ^2 test, $P < 0.01$ Table 1).

Among severely anemic children, those who were trans fused had a lower overall mortality rate (21%) than the children who were not transfused (41%, relative risk

Table 3. Observed weighted mean hemoglobins (g/dl) and frequencies of all hospitalized children on admission, discharge, and follow-up according to receipt of transfusion, malaria parasitemia, and outcome (lived/died).

	Not transfused				Transfused			
	Lived		Died		Lived		Died	
Malaria parasitemia	Positive	Negative	Positive	Negative	Positive	Negative	Positive	Negative
Admission	7.5 (203)	10.2 (81)	6.3 (65)	9.2 (33)	3.9 (143)	3.9 (17)	3.8 (31)	3.9 (14)
Discharge	7.5 (181)	9.9 (79)	6.8 (20)	8.2 (9)	9.2 (140)	8.1 (17)	9.5 (20)	7.4 (2)
4-week follow-up	8.4 (12)	9.8 (172)	8.4 (5)	7.4 (6)	8.5 (65)	10.2 (88)	8.5 (4)	8.8 (4)
8-week follow-up	8.3 (137)	9.9 (125)	–	–	8.2 (92)	10.6 (58)	–	–

Data given as observed weighted mean hemoglobin level (g/dl) and frequency (n, in brackets).

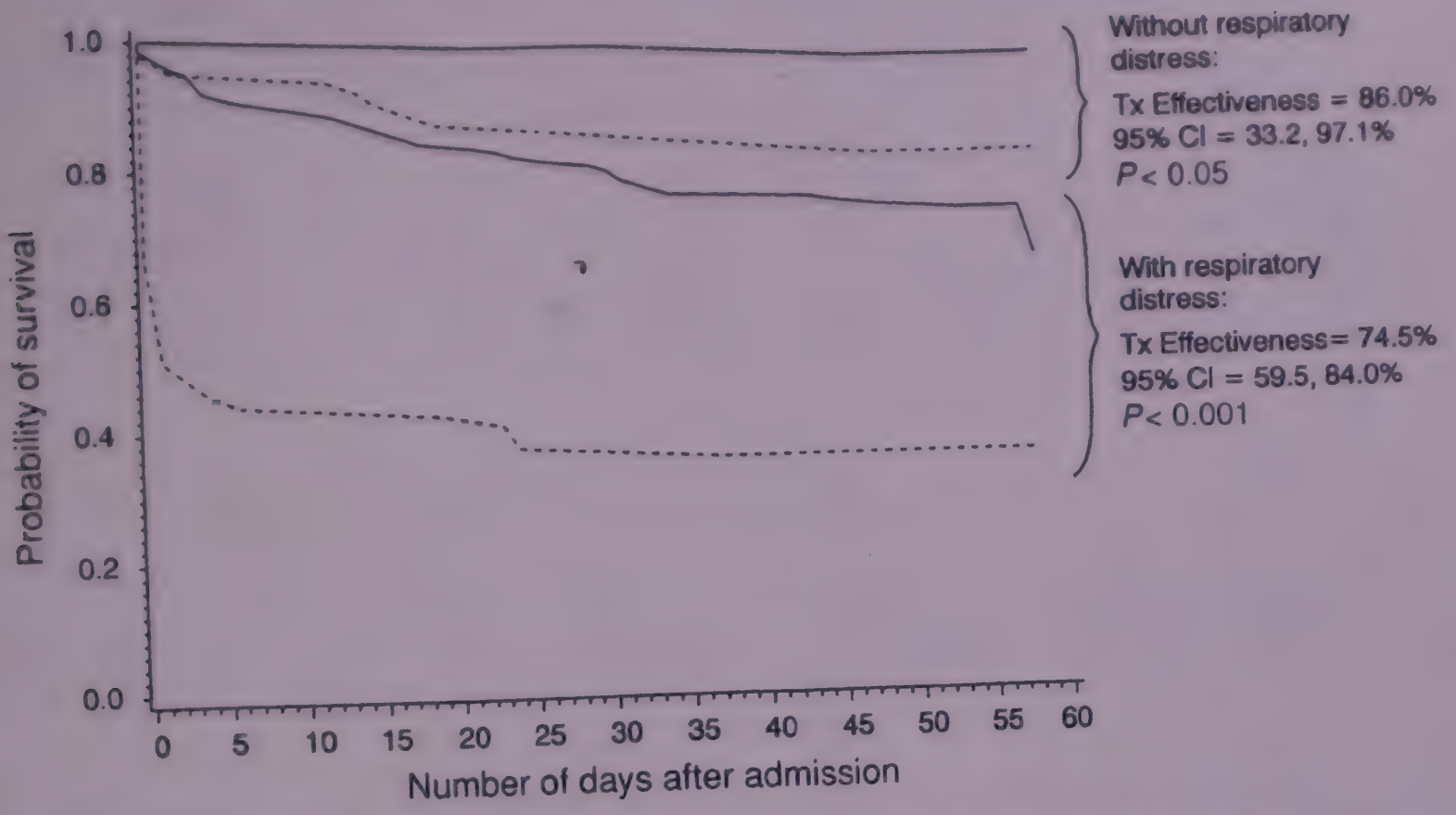

Fig. 1. Kaplan-Meier estimates of the survival functions of severely anemic children who were transfused (solid line) or not transfused (dashed line), according to presence of respiratory distress on admission. Siaya District Hospital, March-September, 1991. Tx, Transfusion; CI, confidence interval.

0.52; 95% confidence interval, 0.36–0.73, Table 2). Transfusion had the greatest impact on the survival of children with clinical signs of respiratory distress on admission (Fig. 1), and the benefit of transfusion in this population was limited to the first 2 days of hospitalization. When the analysis was restricted to those children with respiratory distress who survived beyond the first 2 days of hospitalization, there was no significant difference between mortality rates of transfused and non-transfused children during hospitalization or after discharge (Fig. 2, proportional hazards model, $P = 0.55$).

Severely anemic children without respiratory distress on admission had lower mortality rates than those admitted with respiratory distress, both during and after hospitalization (Fig. 1). In-hospital mortality rates among children without distress were low, regardless of whether they were transfused (none out of 52) or not transfused (three out of 56, Fisher exact test, $P > 0.05$). Among the 12 children without respiratory distress who died, nine died after hospitalization. Unlike those with respiratory distress, children admitted without respiratory distress who were transfused had a lower post-hospital mortality rate than those who were not transfused (3.8 versus 14.8%, respectively; χ^2 test, $P = 0.06$). When the analysis was restricted to children without respiratory distress who survived beyond the first 2 days of hospitalization, transfusion was associated with decreased mortality (Fig. 2, proportional hazards model, $P < 0.05$). Among those without respiratory distress who survived beyond the first 2 days of hospitalization, patient characteristics, including underlying disease, age, parasitemia, and hemoglobin, were similar among patients who lived and died in the transfused and non-transfused groups.

Among all children with severe anemia, the mortality rates remained high in both the transfused and non-transfused groups after hospitalization. Evaluation of admission diagnoses revealed that severely anemic children often had serious concomitant illnesses: 63% had respiratory illness, 33% had malaria, 22% had malnutrition, 12% had bacteremia, and 8% were HIV-seropositive (Table 1). Regardless of underlying disease, the mortality rates were lower among children who were transfused compared with children who were not transfused. In the proportional hazards models, there were no significant interactions between the benefit of transfusion and diagnosis; transfusion did not confer differential benefit to children with different diseases, including malaria.

Among severely anemic children, the levels of hemoglobin at discharge was not predictive of risk of death after hospitalization. Although the mean hemoglobin level at discharge was significantly higher among transfused children, there was no significant difference between the mean hemoglobin level at discharge of children who did or did not survive after hospitaliza-

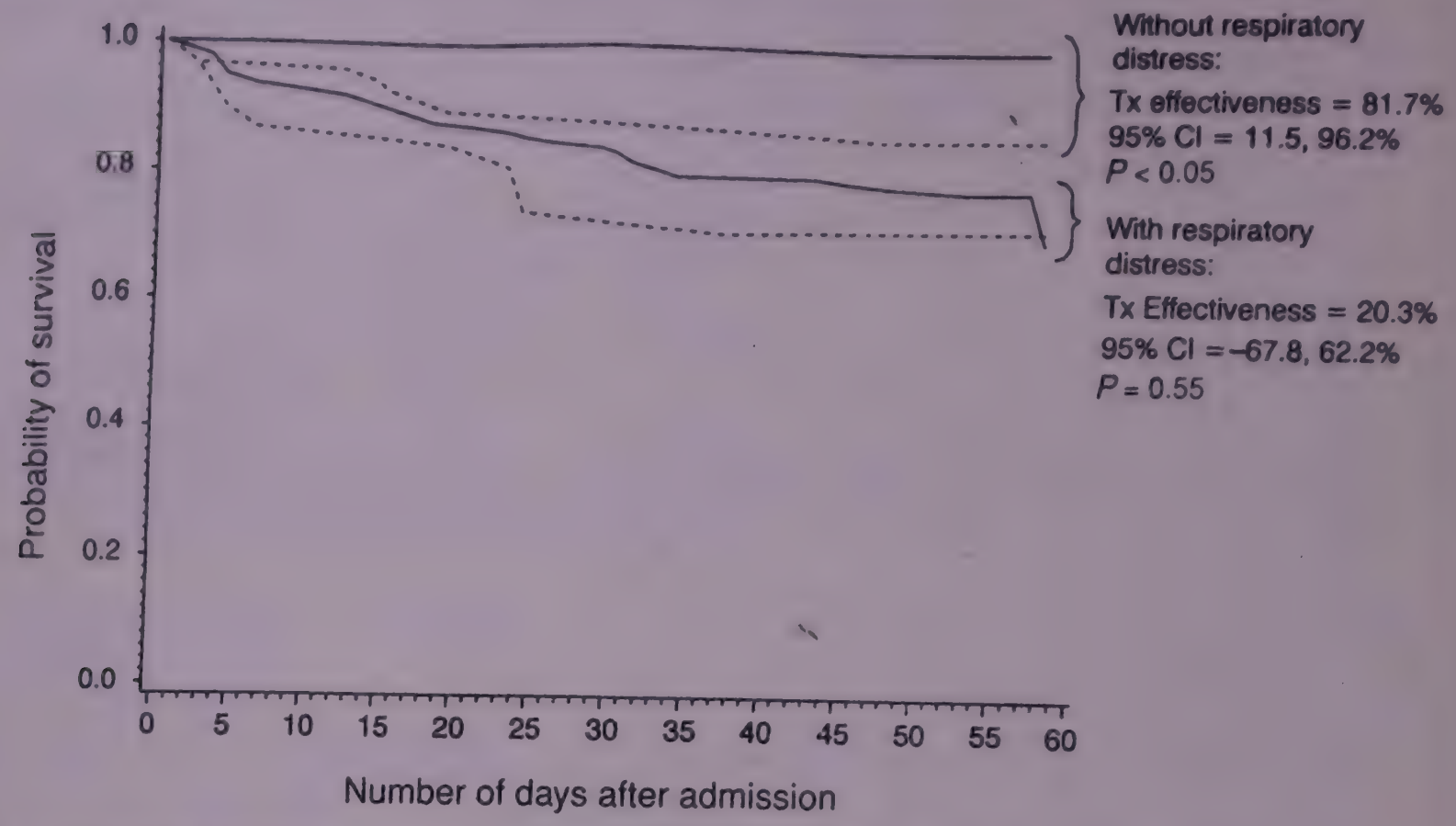

Fig. 2. Kaplan-Meier estimates of the survival functions of severely anemic children who survived beyond the first 2 days of hospitalization, who were transfused (solid line) or not transfused (dashed line), according to presence of respiratory distress on admission. Tx, Transfusion; CI, confidence interval.

tion in the transfused (9.0 g/dl, 9.5 g/dl, $P = 0.56$) and non-transfused groups (5.8 g/dl, 6.0 g/dl, $P = 0.58$).

Discussion

Defining the appropriate use of blood transfusion is an increasingly critical issue, particularly in developing countries, where severe anemia is widespread, the prevalence of HIV infection among blood donors is high, and blood screening is often inadequate. Little information, however, has been available to assist health care providers and policy makers to define the appropriate use of blood in Africa. This study systematically followed all severely anemic children admitted to a Kenyan hospital to evaluate their outcome during and after hospitalization and to determine the effect of transfusion on hematologic recovery and mortality.

Transfusion increased the mean hemoglobin level of severely anemic children during hospitalization and throughout the 8-week follow-up period in an area where malaria, nutritional deficiencies, and other infectious processes associated with persistent hematologic decompensation are prevalent. Malaria-associated anemia is mediated through immune-mediated hemolysis [20], dyserythropoiesis [21], and hypersplenism [22], resulting in shortened erythrocyte survival [23] that persists for up to 3 weeks after clearance of the malaria parasites [24,25]. Although we expected only a brief increase in hemoglobin after transfusion, the transfused children maintained a higher mean hemoglobin level throughout the 8-week study period than those who were not transfused. It is important to note that children who were not transfused also had a significant increase in hemoglobin during the follow-up period, suggesting that if appropriate interim treatment is provided, hemoglobin will increase in a short period of time without the use of blood.

Malaria parasitemia severely attenuated the hematologic recovery of both transfused and non-transfused children, as has been reported elsewhere among children with moderate anemia [19]. Chloroquine continues to be used for treatment of children with malaria in many areas of Africa where chloroquine resistant *P. falciparum* is prevalent. The expanded use of effective malaria therapy among anemic children is needed to decrease the alarming prevalence of anemia, anemia-associated mortality, and the use of blood transfusions.

Practitioners have often been reluctant to reduce the use of pediatric transfusions out of concern for hematologic decompensation after hospitalization. This longitudinal study supports previous cross-sectional studies conducted in Africa which demonstrated the benefit of transfusion, but only when given to severely anemic children with cardiorespiratory distress [11,12,17,18,26,27] and when given within the first

2 days of hospitalization [17]. Our results further emphasize the need for transfusion as a life-saving intervention to be given promptly to clinically decompensated children. This hospital, as well as many others in Africa [10], frequently does not have a supply of banked blood and relies on family members to provide donations. However, the time required to collect and screen blood from family donors typically does not provide blood to patients when it is needed to improve survival. Programs aimed at improving clinical, laboratory and blood bank services are needed to improve the use of transfusions and the immediate availability of blood.

Children without respiratory distress were at a lower risk of death than those with respiratory distress. No benefit of transfusion was found during hospitalization among children without respiratory distress, but lower mortality rates were observed among transfused children during the follow-up period. The hemoglobin levels at discharge, concomitant illness, malaria parasitemia, and parasite density were not predictive of mortality. In contrast, a randomized trial of transfusion among Tanzanian children with hemoglobins between 4.0 and 5.7 g/dl and who had no evidence of congestive heart failure or pneumonia, found no difference in 8-week mortality rates [28]. Additional studies are needed to clarify the indications for transfusion among children who do not demonstrate an acute need for blood; fluid replacement, malaria therapy, nutritional supplementation, and appropriate antibiotics may be more important interventions to promote long-term survival in this population.

Our study was conducted in the context of routine medical care in a rural Kenyan hospital. Transfusion was not randomly allocated, and there may have been bias in who did or did not receive transfusion. However, transfused and non-transfused groups had similar clinical characteristics, and many important potential confounders, such as hemoglobin level, malaria parasitemia, respiratory distress and underlying illness were controlled for in the analysis. Children received clinical and laboratory evaluations on admission and we do not know if their cause of death was the same as that identified at the time of admission. More information is needed to determine the causes of death among anemic children and how improved treatment and supportive care could further reduce the need for blood. Finally, this study was conducted in an area of intense, perennial transmission of *P. falciparum* where chronic and recurrent malaria infections were common. It is uncertain if our findings can be generalized to other areas where malaria transmission is more seasonal and hyperparasitemia may be more prevalent.

In the past decade, severe anemia has been increasingly recognized as an important contributor to mortality among young African children. This longitudinal investigation demonstrated that, regardless of transfusion, severely anemic children had higher mortality rates than children without severe anemia both during and after hospitalization; 15% of the transfused children and 17% of the non-transfused children died after hospitalization. In addition to promoting the safe and effective use of blood, programs are urgently needed that focus on the prevention, early diagnosis and effective treatment of the causes of anemia and concomitant illnesses in order to promote child survival and prevent the high rate of transfusion utilization.

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9

MATERIAL ON HIV/AIDS

SENT BY

MEDICAL MISSION INSTITUTE

AIDS AND INTERNATIONAL HEALTH DEPARTMENT

SALVATORSTR. 22

D-97074 WÜRZBURG

GERMANY

December 1997

International Conference on Home and Community Care for Persons Living with HIV/AIDS
Amsterdam, 21-24 May, 1997

1. General observations: main themes, participants and their (re-)actions

Per definition, the conference highlighted those aspects of care that cover the whole range of professional and lay care *outside the hospital*. The *5 main tracks* medical care, psycho-social care, nursing and home care, self- and community care and prevention in primary care outlined and structured the flow of discussion. Cross-tracks between the plenary sessions allowed the deepening of specific aspects of the respective plenary presentations. Alternatively, it was possible to choose *areas of interest* throughout the disciplines while attending one of about 25 free paper sessions, round table discussions or workshops.

During the 3 ½ conference days approximately one thousand participants were present at the RAI center, a spacy, well equipped building with auditorium and many rooms for the free paper sessions allowing an intense and well organized work. Remarkably, most participants came apparently from resource-constraint countries. I assume, that the majority was financially supported by their respective organizations. However, asking at the conference registration desk I was told that only some 170 participants were holders of conference scholarships sponsored by the WHO, UNAIDS, Dutch Gov. and other major donor agencies. In any case, most of them were experienced care providers and/or other leading representatives of NGOs from all over the world, including many PLWHAs from self-help groups.

At the closing ceremony critisism was raised that 1) only a few presentations were held or translated in French and none in Spanish, and 2) the „free paper presentations were mere repetitions on a small scale (case studies, etc.) of what was said in the plenaries." Despite these shortcomings, the sessions in the different rooms provided ample opportunity for exchange, discussion and learning from each other. Of course, since I could participate in only one out of 25 events at a time between the plenaries, it is simply not possible to give a detailed overview of highlights and pitfalls.

Firstly, I would say that the scope and relevance of the conference was reflected in the wide range and background of participants itself in so far as home and community care can be seen as an innovative approach in resource-constraint countries (DCs), promoted by international organizations, consultancies and donor agencies of industrialized countries.

Secondly, presentations, questions and answers revealed and confirmed the widening gaps between well organized health care services and beneficiary communities in the industrialized countries (ICs) on the one side, and inadequate health care services and silent or striving communities (guided towards alternative health care solutions) on the other.

It became clear that all countries are affected by the pandemic and the reflection on HIV/AIDS in Amsterdam clarified, that beyond all differences, rich and poor countries share *the home and community perspective*. Thus, speakers and participants started often from common sense questions like: What are the characteristics of affected, what are those of care giving communities? Who defines community? Are there coping-models of care in affected communities that can be scaled up?

The lively discussions had quite often emotional overtones. Many statements did not ask too much for scientific evidence but were striking and in any case backed by *personal* experience. Desperation and anger in (DC-)reactions seemed sometimes to find expressions for the 'inexpressible' in the form of straightforward reproaches like the following: „The Red Cross walks around the world calling for voluntarism at community level. But how please can you expect 'voluntarism'? Please kindly demonstrate yourself by doing what you preach!"; „Project plans are all too often made in *air-conditioned* rooms without involving target populations, without assessing their actual needs and without long-term funding perspectives. Didn't you get the point that for volunteers *allowances* were all too often the main reason to leave fieldwork and daily commitments for weeks behind in order to learn and participate in workshops? But we cannot institutionalize voluntarism! Projects will collapse as soon as 'per diems' are withdrawn. Donors have to *undo* what they iniciated!" ... What has been achieved with *your* (the ICs) strategy? ... „NGO business has become a real business. In *our* DCs we notice a community based 'bubble up', a mushrooming of care projects." „What really developed is a *dependency-syndrome*."... „Even 25 years in the pandemic is AIDS in countries like Kenya still associated with curse." „Please practice and follow *your own* recommendations: involve PLWHAs!"

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An underlying and shared theme in many presentations was that *sustainability of programs is* (in DCs) *at stake*. General conclusions indicated that there is an increasing need to *set standards*.

2. Community and home care: the state of the art

Both, plenary and free paper sessions were, of course, principally based on findings of case studies. Irrespective of continental differences and due to the fact that I could attend only one of many sessions at a time, I prefer to indicate with a few strokes (verbatim) a suggestion of each track that may possibly better reflect than scientific study results, mood and - what I would like to call - the 'hidden focus' and 'eye-opener'-function of the event. Such statements are by no means complete, but they reflect the state of the art - at least selective according to my personal point of view:

2.1. Medical care

An expressed need exists in terms of HIV/AIDS guidelines that are scarce and will have still to be developed and incorporated. The existing curricula of health service systems will have to consider *in general* STD/HIV/AIDS-specific needs and interventions for continued training.

The gap between North and South was only occasionally addressed. It goes without saying that ICs have comparatively well organized medical services. More importantly, they even include mental (social, psychological and pharmacological) health services that are commonly available for infected and affected patients in ICs. In contrast, such „western styled" medical health services are (*still?*) inaccessible and unavailable for up to 85% of the population in DCs. People who live in rural areas consult usually (*still?*) traditional healers when they fall ill. HIV/AIDS related training for healers is therefore gradually offered by NGOs in gatherings, workshops and conferences on STD, TB in particular and in PHC in general. Even speakers from DCs with IC-background consistently argued: „it works!" Cooperation between MDs and traditional healers proved promising and useful in counselling, home care visits and complementary (mainly herbal) medication. Of course, concrete concepts of cooperation between traditional and modern care systems have to be seen with caution. There is clear agreement that they must be culturally sensitive and cannot be generalized or 'scaled up'.

It was a shared impression that outreach programs, when planned and guided by MDs who are used to a 'hospital-perspective', tend still to be vertical and „de-contextualized." Combination therapy and even drug supply for treatment of opportunistic diseases is (*still?*) only for few families available. It was criticized that the WHO list of essential medicines does not include relevant drugs for HIV/AIDS patient's care, i.e. drugs for cryptococcal meningitis, herpes, and other opportunistic infections.

In conclusion: „Care needs to be palliative - access to drugs for DCs is paramount. Palliative treatment *is* prevention." Western MDs say: „We are outraged that medication is (*still?*) not available in most countries." ... And Southern participants learned: „ ... medication *will* not be available in foreseeable time."

2.2. Nursing and home care

Needs assessments with community leaders, PLWHAs, health workers and others revealed in high prevalence areas that the awareness level is high - but *negative attitudes prevail*.

Demand-oriented care givers call for continued home care support, including counselling, material assistance (treatment, food, income generative activities, day care centers, volunteers) and training (volunteers; women organizations) for improvements in home-community-hospital referral mechanisms regarding disease episodes. Worthwhile to note: In at least one free paper session the empowerment of women concept was described with sound and provocative arguments as a "man"made(male-made)-ideology: "women do *not* need to be empowered. They *have* compassion."

The central question in most sessions was: what is nursing in AIDS care? A simple and common definition was given: "Nursing is what nurses *do*." Others explained: "Nursing is a creative art - outreach and front line service." If nurses are seen too much in a medical model than new therapies pose new dilemmas. If they are seen from a community perspective, they have learning needs in communication skills so that they are enabled to establish "trust and real contact." They need to share with each other to prevent burn-out. In conclusion: Nursing means: "Daring, caring and sharing." "Nursing is a complex profession and good nurses are artists."

Home based care projects have been initiated all over the world by NGOs but their coverage (with rarely more than 20%) *is still too low*. The search for effective integration in PHC - as suggested by ICs in many statements -

is seen as a priority. Issues discussed were orphan care, women's burden, constraints in regard to continuum of care, etc.
An effective involvement at community level lacks often evidence. - Sustainability in nearly all initiatives (for example, the setting up of drop-in centers, income generating activities, education and care at household level) *depends* on volunteers. As in the medical care track, the collaboration with traditional healers was repeatedly alluded as an issue of increasing importance.
Speakers' general conclusion: In a long-term perspective nearly all will depend on the identification and training of the „right" target groups and material support for the affected families *within the community*. In the years to come, home care along with income generative activities *seems* to be the only realistic and available and sustainable 'combination therapy' for DCs. Cost-effectiveness *is* surely a problem of health care providers but has *also* to be seen from the perspective of families and communities.
Backed by sound data about the reduced capacity in health care facilities (beds; professionals; logistics) speakers from ICs argued that „the home care approach is *inevitable*." Bearing in mind the scarce resources, speakers from *DCs did not and/or could not* see any other *alternatives* to community and home care and were therefore joining hands with their colleagues from the ICs.

2.3. Self care and community care

The already visible severe impact of HIV/AIDS on community and household level mainly in sub-Saharan Africa reveals an ever increasing need for integrated, intersectoral models of care and must involve existing structures. More precisely, throughout this track the main questions have been: how to involve PLWHA? how to improve their access to treatment? How to promote a positive environment?
Like in nursing and home care hinge strong self care responses in HIV/AIDS work on community acceptance and volunteer participation.
PLWHAs „fear living lives in isolation and without activity. "Hope remains a sheer dream without love, food, housing and medicine." Surely, self-help groups are coming up everywhere in the world. The cultural background is relevant, i.e. either enabling or hindering in the development of coping strategies. Therefore, the presentation about experiences can hardly be generalized. However, PLWHAs' problems and human coping capacities are comparable.
I was particularly impressed by the presentation of a young self-confident PLWHA from the Netherlands. His paper was titled 'Self aid as an opportunity to change the care system.' On the one hand, he told the history of a project in Rotterdam where a church-supported self help group started off as a 'living room project' in 1993. Now the project has grown to the size of an institute which plays an important intermediary role in the care for PLWHAs and functions as a gathering place for persons in the target group (see, Program abstract book, abstract, O97).
On the other hand, he told his personal history. The story depicted in a convincing and impressive way his learning process to recognize and overcome inside (personal) and outside (hospital; care system) resistance. In the first place, his own and the care giver's listening capacity had to be developed. 1) Realizing the role of the inner voice (knowing one's need: accommodation, money, medical advice, etc.); 2) exchanging viewpoints among peers (training of ones communication skills) and 3) listening to, and talking with the care givers the 'inner voice' began to be understood. While accepting the care givers' knowledge and limitations the building up of qualities in analysis of the PLWHAs situation' became possible. By and by, the self-help group felt its changing potential and relevance. The self-help group gained increasing influence as an eye-opener for the care givers in regard to the PLWHAs situation. Now, care givers come quite often to the self-help group's own house (Institutional basis) asking for advice in terms of psycho-social care acknowledging the expertise among self-help group. Mutual respect and informal exchange between self-help group and care givers resulted in an increasingly better coordination for care seeking PLWHAs.
Thus, the self-help group is experienced as a sort of 'inner voice' of the care system in regard to HIV/AIDS.
Presentations from DC speakers scarcely indicate the chance for similar experiences. Despite the fact that the legislative reaction to the HIV/AIDS tends worldwide towards the protection of human rights, PLWHAs continue in many countries to engage in risk behavior and are driven underground. Bereavement (depression, loneliness, etc.) leads allegedly to more risk behavior.
However, studies were quoted at the conference confirming that understanding and counselling can change behavior. Other free paper presentations confirmed time and again that increasing pauperization enhances social disintegration which makes it difficult to implement effective programs of the "IC pattern."

2.4. Psycho-social care

Case study presentations in this track addressed particularly needs for psychosocial support to mothers, aspects and constraints of (culture- and context-sensitive) counselling services for HIV-infected children, adolescents, women, IDUs, etc.

In general terms, the focus in low and middle income countries is still on discrimination. Peter Piot underlined this fact: „Discrimination is a mayor source of preventable suffering." Day care centers are increasingly seen as supportive in offering relief and in reducing costs.

2.5. Prevention in primary care

I attended only a few sessions of this track. Main arguments were repeated and reinforced in the opening and again in the closing ceremony. They are consistent with all the above related observations and may be best reflected in the UNAIDS plenary presentation on community mobilization. UNAIDS understands a mobilized community to have certain characteristics of which only a few are to be mentioned here:

- Members are aware - in a detailed and realistic way - of their vulnerability to HIV/AIDS.
- Members are motivated to do something about this vulnerability.
- Members have practical knowledge of options they can take to reduce this vulnerability. ...

The need for NGOs as facilitators and as intermediaries between community-based organizations (CBOs) and health services is out of question. Many free paper sessions focused on NGO work in terms of training and capacity building relevance.

Among the challenges, as seen by UNAIDS, I would like to mention only the following:

- mobilization occurs when a group of people decides to take action, with or without external facilitation.
- Momentum for continued mobilization must come from within the concerned community.
- If it doesn't, the momentum will not be sustained over time.

Paper presentations revealed clearly: HIV/AIDS programs that were launched all over the world in the fight against AIDS did not meet the criteria of sustainability until now. Will they in future?

3. Perspectives

While better care and the decreasing incidence in ICs are seen as a "turning point" and lead to complacency, the situation in DCs is, without doubt, worsening. Generally, the conference plenary and free paper sessions demonstrated that the epidemic is far from being over - it is at its beginning.

As denial and discrimination prevail, access to, and quality of adequate information, voluntary testing, counselling and care "from below" have still to be promoted. This, of course, without relying too much on established governmental, local public health service structures. Notwithstanding, at the same time continuum of care and coordination of all kind with them should be strengthened with, and promoted by NGOs as well.

Between the plenaries and free paper sessions there was ample opportunity for personal exchange with participating NGO representatives. So I had interesting discussions with Latin-Americans and Asians, particularly with Indians screening future challenges at NGO level. Frustration became obvious and understandable in the light of the 'lessons learned'.

All tracks indicated that the main burden in resource-constraint countries will (and has to) rest with the communities. In this regard, arguments from international organizations and IC speakers were striking. However, they seemed not convincing for (even when given by) representatives of the DCs. Successful models of the ICs to cope with the problems can hardly be transferred or copied in DCs. Nihilism that no help can be offered has to be overcome.

UNAIDS catalytic facilitating function together with WHO, pharmaceutics industry, and donor agencies will be crucial for local NGOs and CBOs in DCs. They need assistance in the development of adequate standards and support mechanisms. "We all need to re-evaluate what we are doing."

Integration of home and community care in PHC structures, *wherever they still exist*, is seen as the only alternative in the future.

Clemens Obergfell

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Community participation — a 'must' for enabling HIV/AIDS prevention to 'move beyond awareness raising'

by Jerker Edström and Sarah Lee, International HIV/AIDS Alliance

From awareness to behaviour change

Despite increasing awareness of HIV / AIDS, the adoption of risk-reducing behaviours and less prejudiced attitudes to sexuality, STDs and people living with HIV / AIDS have been slow to develop in many Asian countries. Why?

One explanation may be that many awareness-raising initiatives are both technically weak and socially inappropriate. However, the fuller answer is more likely to lie in programmes' lack of strategies to 'move beyond awareness-raising' — as a central focus for ensuring and sustaining the impact on vulnerability at a community level.

These key issues are central to the work of the International HIV / AIDS Alliance, an international NGO supporting community action on AIDS in developing countries. Since it was established in 1993, the Alliance has supported 'linking organisations' in eight developing countries, including Bangladesh, the Philippines, Sri Lanka and Cambodia.

In each country, the Alliance has provided comprehensive technical, financial and management support, to enable linking organisations to support community-based care and prevention initiatives. Central to this work has been a mission not only to mobilise a broader response to HIV / AIDS, but also to enhance the strategic and technical quality of community action. This approach aims to ensure initiatives which make a substantial and sustainable impact on local HIV / AIDS epidemics.

Promoting community participation

As linking organisations have mobilised community groups to respond to HIV / AIDS in their respective countries, they have found that the majority of prevention projects continue to focus – often exclusively – on basic information provision. This approach has two main limitations.

- First, 'information' and 'correct facts' have often been treated as something objective and independent from the reality of local contexts and perceptions.

- Secondly, many strategies have stopped short of attempting to identify – let alone address – the real life influences on behaviour and vulnerability.

In short, little attention has been given to real people in real settings, within real contexts.. Doing away with narrowly structured, quantitative surveys, the work of the Alliance and its linking organisations has focused on using a flexible 'tool bag' of participatory approaches. These include tools used in participatory rural appraisal (PRA) and participatory learning action (PLA) – methodologies now increasingly common in community development work, yet rarely applied to sexual health. The key components of the 'tool bag' include:

- social maps
- discussion groups
- Venn diagrams
- ranking and scoring
- body mapping
- causal analysis flowcharts
- life-lines, historical time-lines
- trend diagrams
- income / expenditure charts.

All of these 'tools' have been used by, or with, community members to describe and analyse the issues of concern to them, and to explore how those issues link to sexual vulnerability, HIV / AIDS and obstacles to behaviour change. Technical support from the Alliance to linking organisations has been mirrored by support from linking organisations to NGOs through workshops and one-to-one visits. This has enabled the tools to be used in all stages — not just in needs assessments, but also project design, implementation and monitoring and evaluation.

The starting point: defining local needs and aspirations in their real contexts

The Alliance's work in this area started in 1995 with support to HASAB NGO Support Programme, the linking organisation in Bangladesh. Having called for and reviewed project proposals, HASAB realised that community level NGOs could not implement STD and HIV / AIDS programmes

What is an Alliance linking organisation?

- A linking organisation is a national non-governmental partner of the Alliance and an independent NGO support programme. It is managed by local leaders, consults with local stakeholders and sets priorities at a local level.

- Each linking organisation channels a full range of resources – including technical, financial and management support – to community groups, and fosters national collaboration among NGOs and other sectors.

- In about half the countries where the Alliance works, linking organisations are pre-existing NGOs which now include HIV / AIDS in their work in family planning or development. In other countries, the Alliance has worked with local leaders to establish new organisations.

immediately, due to low levels of relevant knowledge, organisational capacity and strategic direction. Although many groups applied for support, their proposals largely focussed on general awareness-raising, with few action strategies orientated towards behaviour change or contextual issues.

HASAB, therefore, developed a strategy to support NGOs in identifying the needs of their communities with regard to sexual health, STDs and HIV/AIDS, as a critical first step in designing more relevant and effective programmes. In selecting projects to support, HASAB emphasised NGOs with the types of background – such as family planning and reproductive health – proven to play an important role in responding to HIV/AIDS, particularly in a low prevalence context such as Bangladesh.

By May 1996, HASAB had supported twelve organisations, with varying levels and types of expertise, to carry out community needs assessments. The majority of these were subsequently funded to implement AIDS prevention programmes. The groups targeted populations believed to be particularly vulnerable to STDs and HIV/AIDS, including women migrant workers and slum dwellers.

For all of the groups, it was their first major step in learning about and responding to both STDs and HIV/AIDS. It was also the first time that they had systematically assessed the reality, needs and priorities of the communities with which they worked.

Building on experience and sharing lessons

Based on its lessons learned from Bangladesh and accumulated experience from AIDS and development programming elsewhere, the Alliance has gone on to promote participation and 'moving beyond awareness raising' in other countries, including Cambodia (in 1996), Sri Lanka (in 1997) and the Philippines (in 1997). In each case, the approach has been adapted to meet the national and local dynamics, capacity and needs of the linking organisation and its partner NGOs.

In Cambodia, for example, it was felt that the level of technical capacity amongst many local groups called for a greater use of more visual tools and techniques to encourage participation. Needs assessment training and field activities were followed by problem analysis and project design workshops using a range of PRA tools to facilitate the process. After these, NGOs held stakeholder consultation meetings in their communities to finalise project proposals and design.

This phase of the process was also used to find out about further technical support needs of NGOs for skills building in particular project implementation strategies, such as peer education and interactive communication skills building. Such training was subsequently provided in workshops and in individual follow-up work with separate NGOs.

In Sri Lanka, Alliance Lanka was assisted to team up with the Colombo-based Institute for Participatory Interaction in Development (IPID), a local non-governmental training institution, to provide technical support to NGOs and to Alliance Lanka staff through training workshops and fieldwork. While Alliance Lanka has gained from IPID's expertise in participatory methodologies, IPID has also benefited from Alliance Lanka's capacity building in sexual health and HIV/AIDS.

In addition to providing con-

Case Study : Progoti Samaj Kallyan Protisthan (PSKP), Bangladesh

PSKP is an established community organisation integrating issues relating to STDs and HIV/AIDS into maternal and child health services among garment factory workers in Dhaka. With the support of HASAB, PSKP initiated its programme development through a community needs assessment targetting young men and women. The participatory process strengthened the relationship between PSKP and the community, and the key findings included:

- large numbers of young single migrant workers with low pay, long working hours and cramped accommodation;
- low awareness about personal hygiene and STDs among both men and women, with workers fearing losing their jobs for taking time off to seek treatment;
- low levels of literacy, particularly among women.

Subsequently, PSKP used the findings of their assessment to develop a broad prevention programme going beyond information provision and based on a participatory approach. It focusses on:

- health education sessions held in the factory during working hours, focussing on personal hygiene and sexual health through the use of pictorial flip charts and card games;
- a night clinic providing STD treatment and condom provision; training of peer educators, followed by peer education between employees;
- continuing liaison and awareness raising with factory management.

tinuous programmatic support, the Alliance has also encouraged linking organisations actively to share their lessons learned. For example, colleagues both from Cambodia and from Sri Lanka have visited Bangladesh to attend a needs assessment training workshop and to accompany HASAB on technical support visits to NGOs implementing participatory programmes following needs assessments.

Furthermore, the Annual Alliance Linking Organisations' meeting has provided opportunities for the Asian linking organisations to share their experiences both among themselves and with NGO support programmes from Africa and Latin America.

The Alliance has also supported linking organisations to gain from the approaches of other institutions in order further to develop their own strategies. For example, in June 1997, linking organisation staff from Bangladesh, Cambodia, the Philippines and Sri Lanka received training during a residential course on participatory methodologies in AIDS programming. On request from the Alliance and others, this course was organised and facilitated by the 'Stepping Stones' team — a UK-based group of sexual health trainers (connected to 'Strategies for Hope') specialising in PLA.

Subsequently, the four linking organisations were supported in how to integrate the techniques and approaches learned into their regular NGO support activities. In the case of the Philippines, the linking organisation called on a resource person met after the training, and began to apply these methodologies in training local NGOs as well as themselves. Following that workshop, PHANSuP is already responding to the specific needs of two local NGOs and provided them with training in PLA methodologies for implementing community-based outreach AIDS education projects.

Results 'on the ground'

To date over 35 local Asian NGOs have completed the process and are now implementing innovative, needs-based programmes. In many cases, using participatory approaches has not only helped the NGOs to improve the quality of their awareness-raising activities, but also to adopt concrete strategies orientated towards behaviour change.

These range from service provision — such as the treatment of common STDs or the promotion and distribution of condoms — to contextual approaches such as empowering vulnerable groups to address the underlying causes of sexual vulnerability, or the power dynamics between men and women, or discrimination against sexual minorities.

In Bangladesh, for example, SHEASS-Bangladesh is providing education, outreach peer support and needle-exchange services to injecting drug users, as well as using discussion groups to address broader contextual issues of vulnerability relating to discrimination against their children. Another NGO in Bangladesh, Concern for Environmental Development and Research (CEDAR), now provides education, outreach, peer support, condoms and STI treatment to lorry-drivers at a key-transit point. This project also responded to the needs of the lorry- drivers for sanitation and recreational facilities and makes use of a centre for continuing discussion groups and traditional folk-drama to address broader contextual issues of vulnerability to STIs, HIV and AIDS.

In Sri Lanka, the AIDS Combat Team is implementing a project for teenage school youth, which both provides information to the youth and works with parents and

Views from stakeholders in the strategy

After a PRA workshop for sexual health needs assessment in Sri Lanka:

"Before the [PRA] workshop, I worried that the Alliance might come and force-feed us another Western 'teaching', but I am pleased that the Alliance helped us find first-class local experts and pleased to have learned that PRA is being used and developed in Sri Lanka by our own people. I think we can all now see how appropriate this type of participation is for helping us work with the community." — **Mr Ekanayake**, Alliance Lanka Provincial Field Officer, after a PRA workshop for sexual health needs assessment

After participatory needs assessment in Bangladesh:

"At first, we wondered why we should do a needs assessment, but the more we learned, the more we realised it was crucial. The findings were astonishing. They revealed things which were completely new to us even though we've been working in our community for twenty years."– **Ahmed Ilias**, Al-Falah, after a community needs assessment among refugees

'Empowerment' through participatory capacity building in Cambodia:

"When we first started working on HIV/AIDS with the Alliance, many of us felt like headless chickens, but now — after going through this long process together — we feel very confident and committed to working on AIDS."— **Kong Samnang** of the Social, Environmental, Agricultural Development Organisation (SEADO), after a local NGO planning workshop.

teachers in order to improve the immediate 'social environment' for sexual health awareness and education. The project is also enlisting trishaw drivers and guest-house managers to provide information as well as free condoms to youths who frequent these establishments for both privacy and sex.

In Cambodia, Indra Devi Association (IDA), which had previously carried out information, education and communication (IEC) activities with sex workers, has — after involving the women — developed a project focussing on group discussions which also includes local police and military (who have various forms of implication in the sex trade).

Meanwhile, the United Neutral Khmer Students' Association (UNKS) is providing peer-education and support for students to help them discuss and deal with peer-pressure related to early and frequent 'sexual conquest', and to build their confidence and capacity about HIV/AIDS through interactive group discussions.

Lessons learned

● Building community participation is a continuing process which does not stop at needs assessment. Effective responses to HIV/AIDS require NGOs to involve their communities at all stages.

● Methodologies are not an end in themselves, and need to be complemented by high-quality information and skills (amongst facilitators) in subject areas such as HIV/AIDS, gender, sexuality and development.

● Effective community action not only requires participatory methodologies and processes, but also participatory attitudes and behaviour by facilitators and NGO staff. This shift can be very challenging and is a learning process which needs to be nurtured within a consistent strategy over time.

● Embarking on a process of building community participation in NGO programming is likely to shift the 'balance of power', or the dynamics, between NGOs and their communities. Although potentially threatening, this needs to be embraced as an opportunity and developed in a positive direction, rather than resisted.

● Involving local technical support providers decreases dependence on international resources and enhances the sustainability and 'institutionalisation' of technical support. Where appropriate human resources are not present, building the capacity of local resource persons alongside experienced regional or international practitioners is advisable.

● Experiences and lessons learned about participatory processes can effectively be shared between organisations and countries. However, strategies need to be carefully adapted to each specific context, rather than replicated. ■

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Blood Safety

The life-saving attributes of blood have generally been recognised by human beings. As early as the 17th century, there were attempts to perform blood transfusions but it was not until this century, after scientists discovered blood types, that blood transfusions became possible.

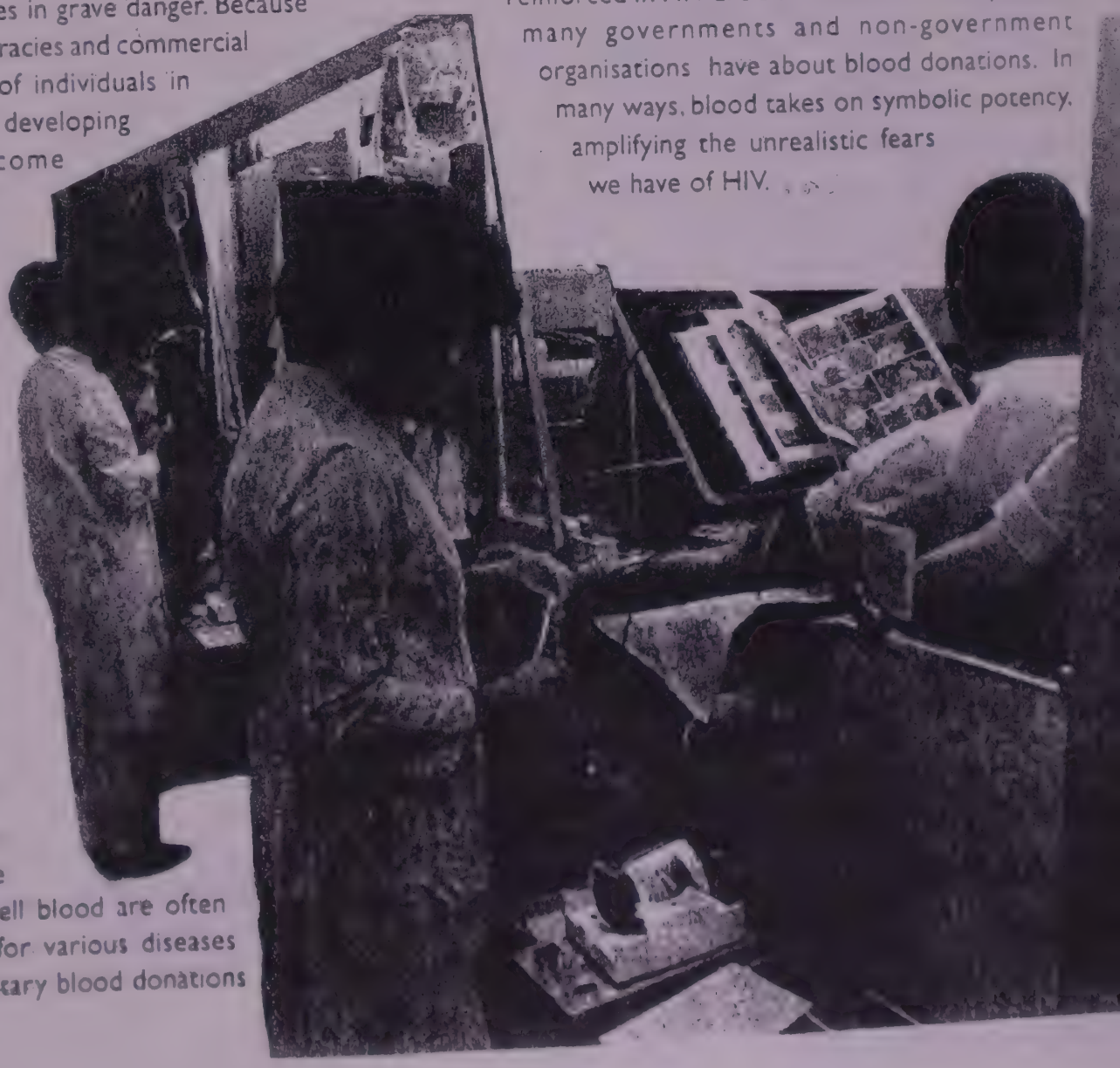
Blood transfusions have since become a mixed blessing. While saving countless numbers of lives, blood transfusions can also transmit a number of serious infections including malaria, hepatitis B, syphilis, trypanosomiasis and HIV.

Worldwide, it is estimated that as many as 10 percent of HIV infections came from treatment with blood or blood products. The reasons for these infections go beyond the medical. As we will see in this issue of *AIDS Action*, even a highly developed country like Japan can have lapses in its public health system, putting its citizens' lives in grave danger. Because of slow-acting bureaucracies and commercial interests, thousands of individuals in both developed and developing countries have become infected with HIV through blood products.

The HIV epidemic has therefore posed a difficult challenge to ensure that people have access to sufficient supplies of safe blood. The challenges are both financial and ethical. It has become clear that commercial blood banks, which buy blood, are no longer acceptable since people who sell blood are often themselves at risk for various diseases including HIV. Voluntary blood donations from healthy adults would be the ideal but there are still many obstacles that prevent more widespread voluntary donations, including beliefs that donating blood will affect one's health.

Blood donation campaigns need to be accompanied by education on HIV. Since blood donors are now often screened for HIV, there should be a system for confidential counselling and referral in case there are individuals who do test positive for HIV.

This issue of *AIDS Action* looks at various aspects of blood and blood donations to show the range of problems that need to be solved to ensure safe blood supplies. While trying to show the serious risks for HIV that come with blood, we also want to show how fears are often exaggerated, built both on traditional beliefs as well as "modern" medical folklore. Social prejudices which have been reinforced in HIV are also reflected in the policies many governments and non-government organisations have about blood donations. In many ways, blood takes on symbolic potency, amplifying the unrealistic fears we have of HIV.



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THIS ISSUE
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BLOOD's many meanings

The HIV epidemic has surfaced many important cultural concepts about blood. Blood plays such a crucial role in human life that people imbue it with meanings and symbolisms that go beyond its biomedical nature. Blood transcends its physical state, and crosses over to the realm of the abstract and the intangible. People in the Asia-Pacific region share a number of common perceptions, although there are also marked differences in the meanings and symbolisms attached to blood. In several countries in the region, blood is a symbol of love, of life, and at the same time, it signifies pain, loss, and violence.

In Japan, "modern" and traditional concepts often blend in, as in the perception that blood types indicate personalities and possible compatibility for marriage or a relationship. Many Asians look for injections even when it is not necessary, and sometimes expose themselves to risks of blood-borne infections. In China, blood albumin injections were being used as a kind of elixir to boost resistance in patients with liver and kidney disorders. In 1996, the Chinese government had to ban a blood albumin product called Wolongsong after they found samples with HIV.

In many Asian cultures, blood is practically equated with life. The Vietnamese perceive blood as the essence of humanity. Other cultures look at blood as a kind of life force. Given such perceptions, it should not be surprising that there might be reluctance to donate blood, because of the idea that one becomes weak by giving up blood.

In most countries in the region, there are generally fewer female donors than male donors. In Fiji, men play the leadership role and are held responsible for finding solutions to problems. In a medical emergency, men are expected to provide the "solution" by donating blood. In Indonesia and the Philippines, a prevailing concept is that women should not donate blood because they "bleed" each month when they have their menstrual period. There is a more scientific explanation for this: women are biologically more prone to anaemia, and an anaemic person should not donate blood. The low status of women in some countries also affects their nutritional status, as women would usually have less to eat than the men, resulting in poorer health. Unfortunately, even medical people tend to reinforce popular misconceptions by barring all women from donating blood. This policy needs to change so more women can participate in voluntary blood donation programmes.

While cultural beliefs sometimes act as a deterrent to voluntary blood donations, it could also serve as the basis for effective strategies. Thus, in cultures where blood is perceived as life, then the act of blood donation is seen as the giving of life. In China, for example, donating blood is seen as a citizen's obligation. The popular Thai royal family has done much to increase voluntary blood donations. Blood donation campaigns are held during the birthdays of the King and Queen, while the Princess of Thailand heads the Red Cross. Likewise, the daughter of President Suharto of Indonesia is active in the blood donation programme. Government officials in the region donate blood to generate awareness and support for blood donation programmes (as well as publicity for their political careers). President Fidel Ramos of the Philippines is a "galloner", a term which refers to those who have donated a gallon of blood.

Several Asian countries have shown how voluntary blood donations can become part of local culture, integrated as one of those practices of social solidarity. In Singapore, National Blood Emergency Exercises are conducted every two years to emphasise the importance of readiness in cases of disasters (as when a hotel building collapsed in 1986, resulting in a massive turn-out of blood donors).

Effective media campaigns are essential for voluntary blood donation to be a success. China's information campaign makes use of posters, mobile cars and television advertisements. There are also shows on television where people tell their life-stories on how blood donations had helped them and their family. In India, a tough and well-built film actor is featured in TV advertisements encouraging people to donate blood and save a life.

The fear of HIV infection has made people more wary of issues regarding blood, sometimes with excessive fears. Thus, law enforcers in Asian countries sometimes become unduly concerned about HIV infection when restraining people they are arresting. In the Philippines and Indonesia, there are periodic rumours about a person going around shopping malls and movie theatres and jabbing people with a syringe containing HIV-infected blood. The fears reached a point, in Manila, where several dozen people actually went to the Health Department claiming they had been victims. A misconception that

Focus

Rakatdan — Jevandan. This is the I national slogan for blood donation, w translates to "Donating blood is offering lif symbol of life as well as a symbol of love, b can also be "pure" or "impure." Blood is pur by charitable acts, while negative actions w make blood impure. Good food, a c environment and a happy life are believed improve the quality and quantity of blood. On other hand, being tense or burdened causes bl to "dry up". Blood also binds people together concept of "being of the same blood" implies kin ties, or being of the same clan or caste. The b that kinship ties can be traced through blood common theme in Indian movies, where the dr climaxes with the leading character's heroic ac donating blood for a long-lost relative.

In real life, "professional blood donc proliferate in India, and commercial blood ba abound in the metropolitan cities. Th professional donors work with middle men w charge as much as Rs. 600 to Rs. 1,000 per bo of blood (approximately US$ 17 to 28). This is m than double the Rs. 150 to Rs. 300 (approxima US$ 4 to 8.5) testing fee charged by the Red Cr and blood banks.

Monetary reward is not the only rea for donating blood. In a group of 20 po graduate university students, all of them h donated blood at least once. They cited vari

as been noted throughout the region is that onating blood can be a mode of transmis-on of HIV and other diseases. Information ampaigns need to address these fears and rovide accurate information.

Aside from stringent laboratory and linical procedures, cultural sensitivity is ssential in developing and implementing lood donation programmes. Blood is life, nd thus demands the same sensitivity eeded in dealing with life's complexities, with illness and health, in taking and giving.

Sources of information:

John Ballard, Elison Bovu, Muhadjir Darwin, M.H Faraaz, Waqatakirewa Lepani, Desti Murdijana, Nguyen Thi Nhu Ngoc, Johanna AP Pattisiana, Rosalia Scrortino Suwanna Warakamin, Vu Pham Nguyen Thanh, Wang Linhong

NDIA

ons for donating blood: as an act of charity; relative in need; for a sense of security that would be able to obtain blood if and when would need it.There were significantly fewer ors, however, amongst a group of lower-me workers, which suggests that access to rmation plays a key role in voluntary blood ation programmes. The staff members of a od bank attached to a private hospital regularly ate blood every three to four months.

There has been increasing concern regarding testing or screening of blood for infectious eases. This was underscored in a recent break of dengue (haemorrhagic fever) in the ital city of Delhi last year. As many as 8,000 ients were hospitalised. Because of the large nber of blood transfusions needed, unscreened od was allegedly used. In early January of this ar, several patients who had been earlier gnosed for dengue and who received blood nsfusions tested positive for hepatitis B.

In recent months,150 blood banks in Uttar adesh and also several in other states like Bihar d West Bengal were closed down for not intaining standards laid down by the state. Some these blood banks were found to be distributing screened blood.

ith research by Avanish Kumar, Meerambika ahapatra and Lester Coutinho

What is BLOOD?

Blood is a fluid tissue that circulates through the heart, arteries, capillaries and veins. It is vital in our body system because it carries nourishment to all the tissues and organs of the body. When there is not enough blood or when its circulation stops, the tissues die of starvation. However, the body is capable of producing enormous quantities of fresh blood as required.

A reduction in blood volume below its normal level may be caused by haemorrhage, a decrease in the total number of red cells, a loss of plasma caused by burns or extensive operations, or a loss of water from the blood due to dehydration or diuretic types of drugs.

Composition of Blood

Approximately 45 percent of the total volume of blood is composed of the Red Blood Cells (RBC),White Blood Cells (WBC) and platelets.The remaining liquid portion is called plasma.

RBC

- made in the marrow cavities of certain bones, especially the spine, ribs and breastbone
- an average person has about 20 trillion red cells
- contains haemoglobin that gives blood its red color and the ability to take up oxygen in the lungs
- iron is a key raw material required by the red cell factories, hence, lack of iron causes anaemia

WBC

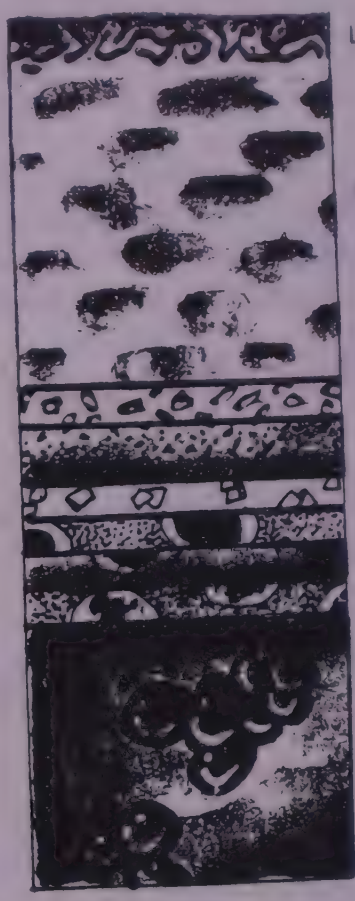
- made in the bone marrow and in certain lymphoid tissues of the body
- there is one white cell for every 100 red cells
- has the ability to defend the body against disease, particularly T-cells, which are attacked by HIV

Platelets

- formed in the bone marrow
- there are about a half trillion platelets in the normal bloodstream
- they help to control bleeding by sticking to injured surfaces of blood vessels and provide a surface for clotting factors to accumulate on, thus plugging up breaks in the blood vessels

Plasma

- composed of 90 per cent water, 7 percent protein and very small amounts of fats, sugar and mineral salts
- plasma proteins include the blood clotting factors



Functions of Blood

1. Transports food materials to the tissues
2. Carries oxygen from the lungs to the tissues and carbon dioxide from the tissues to the lungs
3. Carries waste materials from the tissues to the excretory organs
4. Transfers hormones from the organs of production to the target organs
5. Acts as a defense mechanism against infection through the activities of certain white cells and immune bodies in the bloodstream
6. Assists in the maintenance of constant body temperature and alkalinity of the tissues

Adapted from A Primer on Blood and Blood Donation. Produced by the Department of Education, Culture and Sports, Philippine Blood Coordinating Council, Department of Health and Philippine National Red Cross

Strategies for SAFE BLOOD

Receiving an HIV-infected blood transfusion carries more than a 95 per cent risk of HIV transmission. AIDS Action explains how blood can be made safe.

Donating safe blood

The best way to ensure that donated blood is free from infection is to encourage donation by people who are:

- unpaid and willing to donate blood voluntarily, responsibly and regularly
- at low risk of HIV and other infections transmitted by blood
- healthy and fully grown in order not to affect their own health, and not pregnant or anaemic, or suffering from any infections
- informed about the tests to be done on their donated blood, including HIV.

Schools, universities, church groups, community centres and workplaces provide opportunities for educating and recruiting people at low risk of HIV. Public education and sensitive counselling can help people to decide not to give blood if they feel they have been at risk (self-exclusion).

Avoiding unsafe donations

Using donors who are paid to give blood is likely to lead to a commercial, often illegal, blood trade and an unsafe blood supply. The people who have to sell their blood in order to make a living are often those at most risk of serious communicable disease.

Blood donation should never be compulsory, and should not be carried out in institutions such as prisons or the army. Even if the authorities encourage voluntary donation, it is often hard for people to decide freely whether to give blood. Positive results often lead to discrimination, such as isolation in prisons or dismissal from army service.

In rural areas where blood supplies are scarce, members of the patient's family are sometimes asked to donate their blood. However, this should be avoided unless there is no alternative. In some areas where HIV is common, up to half the blood donated by family members is HIV infected and has to be destroyed.

Health workers faced with this situation should take the family member's blood for testing but use an existing tested unit from the hospital blood bank for the patient. The donor should be told that their blood will not be used for their own relative but, if proved free from infections, will instead be deposited in the hospital blood bank.

Family donors should always be counselled before donating and their blood only collected if they meet the national criteria for blood donation (see pages 6 and 7). If they do not have HIV they should be encouraged to become regular donors.

Screening blood

All donated blood needs to be tested for the presence o infections that are transmitted by blood: HIV, hepatitis B and syphilis. Tests for hepatitis C, Chagas' disease and malaria may be carried out, depending on local disease prevalence and national policy. Blood giving unclear or positive test results for any of these conditions should not be used and be safely disposed of, by incineration, for example.

Occasionally a person whose blood tests HIV negative does in fact have HIV. This is usually because of the 'window period'. HIV tests do not detect HIV itself but antibodies produced by the immune system in response to infection with the virus. However, it can take up to three months for these antibodies to be produced.

During the window period an HIV antibody test will produce a negative result even though HIV is present in the blood and may be transmitted. It is therefore very important for anyone who has had possibly risky activity during the past three months to be advised not to give blood.

HIV test kits used by blood collection services must be of high quality and the instructions followed exactly. The test used depends on local hospital or national recommendations but it needs to identify all possible HIV infections. This means that the test must be highly sensitive, meaning that it has a low number of false negatives (blood testing negative which is in fact positive).

If a blood bank is testing at least 40 blood samples each day an ELISA test will be the most cost effective. If less than 40 blood samples are tested a reliable simple/rapid HIV assay will be more cost effective than an ELISA test.

However, highly sensitive tests can produce false positive results (blood testing positive which is in fact negative). Therefore a positive result does not necessarily mean that the person is infected with HIV.

People should not be informed of their results after only one positive test result. A second blood sample must be tested. Ideally the test needs to be a different test. It does not need to be a Western blot

Key points

Blood transfusion services use three main strategies to reduce the risk of transfusing infected blood:

- minimising the number of HIV-infected blood donations by recruiting and counselling voluntary unpaid donors who are at low risk of HIV
- testing (screening) all donated blood for HIV and other infections transmitted by blood and safely disposing of infected blood
- reducing the number of blood and blood product transfusions.

Blood transfusion services are developing these strategies by: setting up a donor selection process; training staff in education and counselling skills; providing a regular supply of equipment for collecting, screening and storing blood; using blood transfusion guidelines; and ensuring quality control.

st but should be done independently of the first test and curately checked.

People should be informed of their HIV infection only if the sults of both tests are positive, and if counselling and follow-up pport are available.

educing blood transfusions

Despite rigorous HIV screening procedures, a few infected ood units may go undetected. It is important to reduce the number transfusions to the minimum, to keep the risk of infecting patients low as possible and to save costs and blood product use.

Blood transfusion guidelines can help prevent over-use of blood oducts. For example, in rural Tanzania, staff at district, mission and ferral hospitals were trained to use guidelines including:

- precise indications for prescribing transfusions to children, egnant women and other adults with severe anaemia; to patients th acute blood loss; and during, before and after operations
- using blood substitutes where possible such as saline, for example replace the amount of fluid in circulation after a haemorrhage
- using the patient's pre-collected own blood when surgery is planned
- not using a single unit transfusion of blood as a 'tonic' (often ed for 'topping up' blood when someone is weak from anaemia after an operation).

The project also recommends the following strategies:

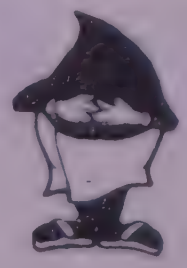
- setting up a blood transfusion committee to monitor blood use
- regular continuing education and supervision on using guidelines
- clinic meetings where blood transfusions can be discussed by staff
- ensuring that staff provide clear reasons when prescribing ood transfusions on a request form.

Most importantly, illnesses and conditions requiring blood ansfusions need to be better prevented. In developing countries most blood transfusions are given to children and women for anaemia or pregnancy complications. Community health care programmes need to provide treatment for malaria and worms for pregnant women and vulnerable children, and to improve nutrition, water supply and sanitation.

FEARS ABOUT GIVING BLOOD

'I'm worried that my test results for HIV or syphilis will be made public.'

Good systems of confidentiality need to be developed and clearly explained to donors.



'I'm scared of being infected with HIV while giving blood.'

There is no risk of infection because a new needle and syringe are used for each person.

'I'm worried that giving blood causes physical weakness or infertility.'

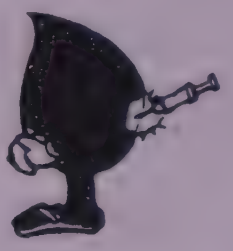
Many donors have given blood over 50 times, up to four times a year, without any harm to their health.

'I can't give blood because I think I'm anaemic.'

Before taking blood, a simple test is performed on a drop of blood taken from a finger prick to find out if the person is anaemic.

'I hate needles.'

A local anaesthetic is applied to the skin to make sure that giving blood is not painful, and the donor does not have to watch the procedure.



'It's too inconvenient and I'm too busy'

Giving blood can mean life itself for a patient, and even the busiest people find time to donate.

Adapted from Fiji Red Cross leaflet.

With thanks to Dr Jean Emmanuel, Chief, Blood Safety Unit, WHO; Dr Robert Beal, Interim Director, Blood Dept, IFRCRC; Mr David Mvere, Technical Director RK Shamu, National Blood Transfusion Service, Zimbabwe; Dr Zarina Bharucha Head, Dept Transfusion Medicine, Tata Memorial Hospital, Bombay, India

Source for Reducing blood transfusions:
TANESA Project, PO Box 434, Mwanza, Tanzania.

Safe blood and safe

ucation and counselling for donors not only contribute to making the blood supply safe, but also to promoting safer sexual behaviour

Public education

Basic information is provided in leaflets, newspaper articles and television or radio advertisements. Donors can be recruited during campaigns or talks at church groups or schools. Messages should emphasize the positive reasons for giving blood, including stories about lives saved by blood transfusions. Education should also highlight the serious need for people to be responsible donors who do not put patients at risk of HIV or other infections.

Before donating blood

When people come to the blood collection centre or mobile van, it is helpful to give a talk or show a video to small groups about the counselling and blood collection process.

The key messages are:

- what happens when you decide to give blood
- why regular safe donations are needed
- your donated blood is tested for HIV and other infections
- basic facts about HIV and HIV prevention
- your confidentiality is guaranteed
- the importance of deciding not to donate blood if you think you may have HIV or another infection (self-exclusion)
- where to go for counselling and HIV testing, if you wish.

One-to-one counselling

Ideally each potential donor should have a one-to-one talk with a trained health worker before blood is collected. Staff need to be able to provide accurate information, ask and answer questions sensitively, and refer people to other sources of support.

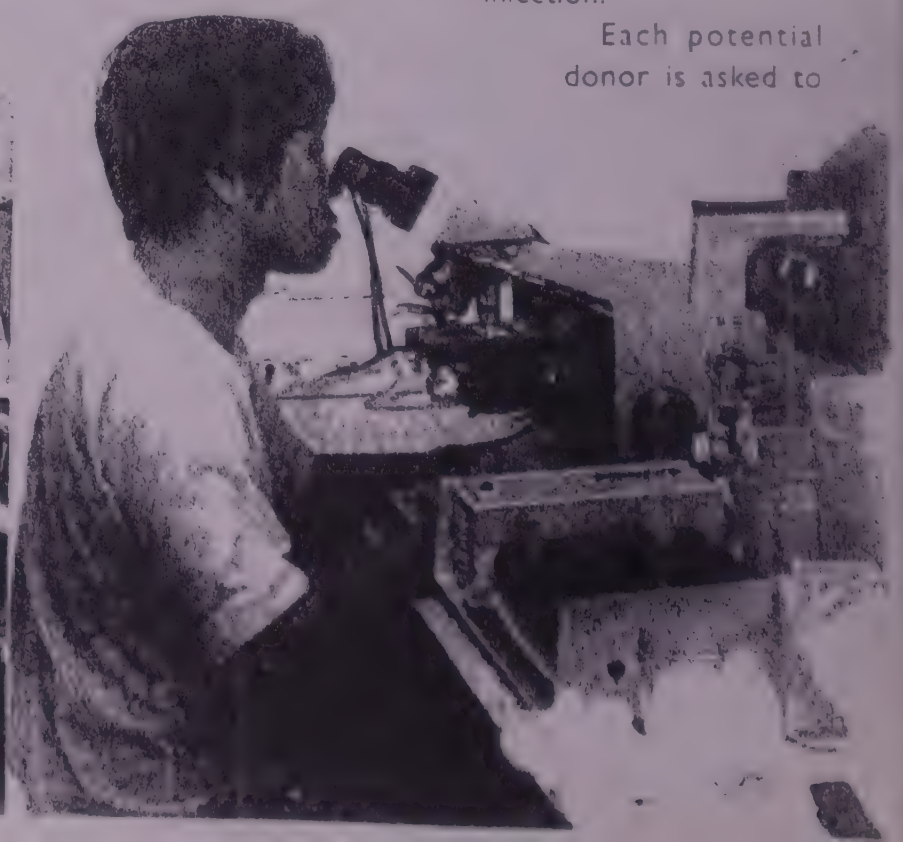
People wanting to give blood may not have seriously considered that they may have HIV infection. However, it is also very important that people are discouraged from using blood services as testing centres. The counsellor or nurse should check that the person understands how HIV can be transmitted and explain which tests will be done and why, and what the window period is (see page 4). He or she should also explain that blood may not be used for a number of health reasons, including anaemia or syphilis, which can be cured.

Donors need to know why personal questions, for example about their sexual activity and injecting drug use, are necessary. Discussing these issues helps people to decide whether they should donate blood or if they should exclude themselves because they may have been at risk of HIV.

The Namibian transfusion service found that potential donors had difficulty filling in a 'self-exclusion' questionnaire on their own. Now a trained nurse goes through it with each person and answers any questions. The questionnaire lists activities which exclude the person from donating blood, such as ear and skin piercing, tattoos or traditional skin incisions, any past sexually transmitted infection or common HIV-related symptoms such as night sweat, swollen glands or persistent diarrhoea.

In Honduras the Red Cross National Blood Programme provides pre-test counselling for voluntary blood donors. Leaflets contain information about HIV and the importance of not donating if the person has engaged in activities associated with high risk of infection.

Each potential donor is asked to



sex

read the brochure. A nurse encourages questions and checks that the information has been understood. The nurse then asks specific questions about sexual behaviour such as all forms of unprotected sex including sex with other men and any history of sexually transmitted diseases. When this counselling session was introduced in 1991, HIV prevalence among blood donors dropped from 0.38 percent in 1990 to 0.19 percent a year later, even though overall numbers of Hondurans with HIV continued to increase.

If they do give blood, donors also need to decide whether they wish to know their HIV test results. However, as explained on page 4, this option should only be given if a second test is possible, and counselling and support services are available.

After donating blood

It is very difficult for many blood transfusion services to provide post-donation counselling for people with positive test results. If HIV counselling and care or treatment services are not available, people should not be informed of their results. However, referral links

can be set up with existing counselling organisations.

Negative donors are sent newsletters and invited to donate again, or to join a blood donor association. This provides an excellent opportunity to reinforce education they received before donating blood. It encourages them to become regular donors, as well as talk to others about safer sex and safe blood.

With thank[illegible] National Blood Programm[illegible] Honduras, Mr [illegible] Alvara[illegible] Dr S Kalibala, UNAIDS, Dr Y Shiep, Dr Cha[illegible] Nuchpraypon, Director, National Blood Cen[illegible] Thai Red Cross Society, European Commis[illegible] 1995. Safe blood in developing countries: [illegible] lessons from Uganda

Blood-Borne DISEASES

Before donating blood, potential donors are screened to determine if they are healthy enough to donate blood, and that they do not have diseases which could be transmitted through blood. Aside from HIV/AIDS, some common blood-borne diseases are hepatitis B and C, malaria, filariasis, and syphilis. Some of these diseases may not have any active symptoms, thus tests are necessary to find out if the blood is infected. Below is a description of common blood-borne diseases:

Filariasis refers to a condition characterised by the presence of nematodes (tiny worms) which attack the lymphatic system. Female worms produce microfilaria which are released into the bloodstream. Filariasis is commonly transmitted through the bite of an infective mosquito. It is possible for those with filariasis not to have any symptoms, although in a number of cases the following signs may be observed: recurrent fever, enlargement of the lymph nodes, swelling of the limbs, encephalitis (enlargement of the head), and breathing difficulties.

Hepatitis B and C. Hepatitis B is a viral disease which affects the liver. Common symptoms are tiredness, yellowing of the skin and eyes, and loss of appetite. However, a person may be infected with the virus and not have any symptoms. About 10 percent of cases develop chronic hepatitis, remain infectious to others, and may develop liver disease which can lead to death. Aside from blood transfusions, hepatitis B is spread through unprotected sex with an infected partner. Hepatitis C, on the other hand, is a recently discovered form of the virus which is transmitted mainly through blood, and causes chronic disease in most people infected.

Malaria is commonly spread through the bite of an infective mosquito. The symptoms of malaria are chills, high fever, and cold sweats. Chronic malaria can cause anaemia and an enlarged spleen. Since malaria is primarily spread by mosquitoes, the disease is widespread in tropical areas where mosquitoes thrive.

Syphilis is a sexually transmitted disease, and its symptoms may go unnoticed. Its initial symptoms include a painless sore in the genital area. Women may not notice the sore if it is located on the vaginal walls. The secondary stage of the disease is a rash and swollen lymph nodes. If untreated, syphilis can cause serious problems to the heart and to the brain.

Testing positive

Providing counselling for donors who test HIV positive poses key challenges for blood services and counselling groups.

Ideally, people who may be HIV positive should be encouraged not to give blood. However, if the person decides to give blood, they should be given the option of knowing their results.

They should only be informed if two test results are positive and follow-up counselling and support are available. After talking with a counsellor, people may decide not to give blood but may also want to be referred for an HIV test. Many blood services are trying to link up with NGOs and hospital counselling services.

In 1993, Zimbabwe's blood service reviewed its notification systems after some donors expressed anxieties about confidentiality, especially in relation to HIV, and numbers of adult donors were declining. In the past, people were referred to their doctors, but many donors either did not have a doctor or were reluctant to discuss HIV or syphilis infection with them.

Now, donors with positive test results for HIV, syphilis or hepatitis are informed by mail that they have an unspecified infection, but are offered counselling and follow-up at an organisation or doctor of their choice (who are also sent letters explaining the situation).

However, NGOs which provide counselling have difficulties in following up donors. In Zimbabwe some NGOs reported that less than half of the people referred to them came for counselling. Common reasons included: people's unwillingness to go to the local 'AIDS centre'; fears about which infection they had, or that they had HIV; worries about being referred to a counsellor whom they already knew personally; difficulties in travelling to the counselling centre during its opening hours; and problems with the postal service.

HIV counselling services often receive referrals for other blood infections, such as syphilis or hepatitis, but counsellors may not have enough information on these illnesses.

Young donors

In many countries school age donors are recruited because they are at low risk. It may be best only to recruit students who are legally adults, who therefore can consent to being tested and to receiving their test results without their parents' permission.

Some blood services invite parents to approve the participation of their children, although there is still debate about whether to involve parents in counselling if the young person tests HIV positive. It may be more difficult to confidentially inform and support young people who test HIV positive, especially if they are at school, and if other students are becoming regular donors.

Counselling services and blood transfusion centres need to have a policy on recruiting young donors, and counselling them if they are diagnosed HIV positive.

Other HIV testing options

Individuals who are worried that they have HIV often use blood collection services in order to find out their HIV status, rather than to donate blood. This increases the risk of an unsafe blood supply. Independent counselling and testing services help the blood supply to become safer, by making sure that people who want an HIV test can obtain one.

With thanks to Dr S Kalibala, UNAIDS and Mr David Mvere, NBTS, Zimbabwe.

Counselling organisations can help the blood transfusion service by:

- encouraging head teachers or employers to allow enough time for pre-donation education and counselling, and post-donation counselling and support
- educating the blood service staff, head teachers and employers about HIV to make sure that confidentiality is respected and discrimination does not occur

Blood services can help counsellors by:

- organising adequate pre-donation counselling before taking blood, to help people decide not to give blood if they have engaged in risky activities, or to encourage them to return for counselling if they are notified of possible positive results
- ensuring that, if the first HIV test is positive, a second test is carried out and is positive, before informing someone that they have HIV
- making sure that referral information is passed to the counselling service before it is mailed to the donor so that the counsellor has full information and time to prepare
- making sure that the donor information contains information about the advantages of knowing results.

Effective counselling

- Wherever possible, the same person should do the pre-donation and post-donation counselling, before referring.
- Pre-donation counselling should include talking about what it means for a person to know their HIV status
- Blood donors should know that they will be referred if their blood cannot be used, because of other infections, malaria or anaemia and not only HIV.
- Counsellors need information about infections such as hepatitis and syphilis, in local languages, and to know where to refer people for treatment.
- Donors need to understand the meaning of an unclear or false positive result.

Towards better counselling

Role-play

This training exercise aims to help counsellors think about the importance of trust and what might happen if someone's test results are made public.

People's greatest concern about giving blood is that their confidentiality will be broken.

Confidentiality is essential both to protect people's privacy and help them to feel safe about discussing their personal experiences.

1 Introduce the exercise by raising the issue of confidentiality. Remind the group that people feel more able to discuss personal issues and feelings if they trust that the counsellor will not tell anyone else without their permission.

2 Split the group into pairs. Ask each person to think of someone they trust and write down ten words describing them, such as friendly, close, and honest.

3 Ask each pair to read out their words to the larger group and write them on a large sheet of paper, noting common words.

4 Split the group into smaller groups of three or four people to discuss the following questions:

What do you need to say and do when you are counselling someone to help them have confidence in you? What do you need to do to enable them to keep trusting you? What might happen when confidentiality is broken? What are the benefits of maintaining confidentiality? Invite one person from each small group to report back to everyone.

5 Then give each small group a situation (two examples below), and ask them to discuss their reactions and feelings about being in that position.

You have been diagnosed with HIV. During counselling the counsellor promised that he was not going to tell anyone about your diagnosis without your consent. Three days later you receive a phone call from a friend who wanted to confirm the news that you had HIV. Your friend has heard this from your counsellor.

You work in a factory and the blood collection team arrives. While you are doing the questionnaire you mention to the nurse that you were treated for a sexually transmitted infection four months ago. Your blood is not collected. Later a friend mentions to you that the person next in the blood donation queue saw your form and is telling all your work colleagues that you have AIDS.

Is this situation likely to happen? Why might it happen? How would it make you feel? What would you do or say in that situation? As counsellors, how would you prevent it from happening?

Source: Mr T R Makoni, National Blood Donor Counselling Co-ordinator, NBTS Zimbabwe.

Assessing personal risk

This activity helps counsellors to think about how they handle risk in their own lives, and increase their understanding of why other people take risks and their feelings about this.

Before deciding to take an HIV test people need time to think about what it may mean to discover they have HIV. Many people feel anxious about discussing their personal risk of HIV (often for the first time) and are worried about being judged.

1 Invite participants to consider the following on their own for a few minutes:

'Think back on your own life and identify any occasion when you took a risk –related to sex and relationships, to work or to money, for example. It may have been a small risk or a big one that was very important to you at the time.'

- What factors influenced your decision to take a risk?
- What were your feelings at the time?
- What was the result of taking that risk?
- Do you generally take risks?
- How do you view risk taking in others?

How does risk taking among your friends affect you?

- How does this affect your attitude towards the risk of HIV?

It may be useful to write these questions down.

2 After a few minutes ask everyone to choose a partner and share as much of their situation as they wish. Each person should talk for a few minutes and then listen to the partner's story.

3 Invite everyone to join the full circle. Encourage them to explore links between how people deal with risk and ways in which it may affect their responses to HIV/AIDS.

It may be useful to make the following points:

- We often feel that it is all right to take risks if they turn out well. But we tend to blame others if they take risks and things go wrong.
- We are generally much less harsh in judging ourselves than we are in judging others. Is this fair?
- We are all taking risks all the time.

4 Then invite people to link this discussion with their counselling work. How can they introduce the subject of risky sexual behaviour without being judgemental? How can this be linked to information about safer sex and reducing the risk of HIV infection?

Source: Working with uncertainty, published by FPA England.

When Money is More Important than Blood:

Blood Scandal in Japan

Ibarra Mateo

TOKYO - Of the 5,000 haemophiliacs all over Japan, 1,872 or about 40 percent were infected with HIV through transfusions of blood and coagulants. As of the end of 1996, 456 of these haemophiliacs have died.

The "blood scandal," as it is described in the media, has captured world attention because Japan is one of the most developed countries in the world. People forget, however, that similar problems have been reported in other developed countries, including Canada and France, where law suits and criminal cases have in fact been filed against health officials. The Japanese case is perhaps more dramatic because of the much longer delays that have taken place before the case was brought to court, suggesting a cover-up among government officials.

Early Years

The story starts with the HIV epidemic beginning in the west. As early as July 1982, doctors in the United States had linked HIV infection with transfusions of non-heated (unsterilised) blood products, prompting pharmaceutical companies to switch to selling heat-treated blood products the following year. While the non-heat treated blood products were being recalled in the US, Japanese medical practitioners continued to administer such products. It was not until July 1985 that the Japanese government authorised heat-treated blood products and even then, it did not order drug manufacturers to withdraw unheated products from the market. Investigations now show that the unheated blood products may have continued to be on the market up to 1988.

In 1989, Japanese haemophiliacs first filed lawsuits against the government and five pharmaceutical companies that distributed tainted blood but it was not until 1996 that a settlement was reached, with companies agreeing to give a one-off payment of Y45 million (about US$450,000) to each plaintiff or the plaintiff's family. For plaintiffs who develop AIDS, the companies agreed to an additional payment of Y150,000 (US$1500) per month.

Collusion Between Health Bureaucrats and Commercial Interests

The settlement only marks the beginning of more investigations, this time into the actions of government officials, who claim that they were not aware of the risks. The Ministry of Health and Welfare had until recently denied the existence of official files relating to blood supplies. Yet, it has been shown that as early as July 1983, an item on the "handling of blood products" was deleted from the agenda of a meeting of the Health Ministry's AIDS study team. This particular item in the agenda has significant implications to the ballooning of the HIV-infection through blood transfusion. The insistence of the senior officials effectively killed the discussion of the early introduction of heated products and in effect affirming the continuation of the policy of administering the unheated blood products.

The Japanese blood scandal exposed the problem of close relationships between government bureaucrats and drug companies. It is a common practice here in Japan that retiring bureaucrats are offered positions in the private sector. This practice is called "amakudari" (sent from heaven). The private sector also funnels a substantial amount of money to academic institutions that conduct scientific research.

Two health officials and several Japanese pharmaceutical companies are in the middle of this drama. One was Dr Takeshi Abe, regarded as Japan's leading expert on haemophilia. Prosecutors have charged that Abe, in his capacity as chief of a division of Teikyo University hospital in charge of patients such as haemophiliacs, was in a position to decide the hospital's treatment policies for haemophiliacs. Prosecutors say Abe became aware of the infection risk in administering unheated blood products in September 1984 after a US expert sent him the results of blood sample examinations showing that 23 of the 48 haemophiliacs treated in his hospital had been infected with HIV. The prosecutors have also alleged that Abe received an equivalent of about 100 million yen (about US$1 million) as donations from drug makers who provided the unheated blood products. Abe was known to be a protege of Green Cross founder Ryoichi Naito. Although Naito died in 1982, his aggressive business philosophy lived on. Naito was once quoted as saying: "Money is more important than blood."

There were also allegations that Abe prevented a foreign drug-maker from starting a clinical trial of a concentrated, heat-treated blood product before Japanese drug manufacturers were able to begin clinical testing of similar drugs.

Another government official, Akihito Matsumara, faces charges of professional negligence arising from the death of two patients who received contaminated coagulants imported from the United States and approved by the Japanese government. From July 1984 until June 1986, Matsumura was the chief of the Japanese health ministry's now defunct biologics and antibiotics division which was at that time in charge of examining and approving blood products. Prosecutors also claimed that Matsumura knew fully well of the HIV infection risk from the unheated blood products as early as November 1984. At that time, prosecutors claimed that the findings of a blood sample examination of

the haemophiliacs were announced in a meeting of the health ministry group on post-transfusion infections.

Matsumara has defended his failure to recall the controversial blood products because this would have led to huge financial losses on the part of the Japanese drug companies. Prosecutors have used this statement to show that Matsumara was more inclined to protest the interests of local drug companies.

The Seven Long Years to Court Victory

In March 1996, seven years after the victims of what was described as Japan's worst medical disaster initiated court proceedings against the Japanese government and five Japanese drug firms, victory came to them in the form of a court-arbitrated settlement. The Japanese pharmaceutical firms involved are Green Cross Corp., Bayer Yakuhin Ltd., Nippon Zoki Pharmaceutical Co., Baxter Ltd., and Chemo Sero Therapeutic Research Institute. Both the victims and the lawyers decided to jump start negotiations when the court suggested the idea that the defendants should admit their responsibility in causing and spreading the death of hundreds of haemophiliacs. This appealed immediately to the plaintiffs who had been pressing the defendants to admit their guilt and responsibility. It is said that during the seven-year long battle, almost half of the plaintiffs had died of AIDS and that every five days that passed, one case of AIDS breakout or death due to HIV infection is recorded among the original plaintiffs.

The court settlement stated that the drug companies should accept the primary responsibility in connection with the blood disaster and severely criticised the Japanese health ministry by declaring that it failed to take appropriate steps to see to it that the drugs sold in the market are safe. Touching directly on the government responsibility, the court said that one of its agencies in charge of pharmaceutical administration has "responsibility to take action to redress the damage suffered by many patients" and to extend "relief" to these victims. While the court stated that primary responsibility should be accepted by the drug firms, it also said that the government must share the responsibility especially that the health ministry helped in the spread of the HIV infection by concealing relevant information from haemophiliacs. The unusually strong statements from the court stopped short of saying that the Japanese government has also the legal responsibility to pay compensation money to the victims.

To most observers, what prompted the usually reserved Japanese court to issue such a strongly-worded statement was the snowballing public opinion supporting the victims. Public support started mounting when a 21-year-old victim decided to end his silence. The courageous Ryuhei Kawada, a student of Tokyo Economics University, gave a human face to the hundreds of HIV-infected haemophiliacs who were suffering in silence. Soon Kawada was a familiar face explaining the HIV-infection that was caused by the unheated blood products on television stations. He was the figure standing on platforms in rallies in front of the health ministry building. To Kawada's courage, the Japanese public's answer was strong support that took the form of attending the victims' protest action and invitations to various forums where they can listen and understand further the plight of the victims. "Not much truth has been revealed despite the promises of the defendants to make utmost efforts to disclose the true story behind the disaster," Kawada told a local newspaper here in an interview. "I could never be satisfied until the truth is disclosed Without knowing the truth, the defendants would be unable to offer sincere apologies to us because they could not understand what was wrong (with their actions)," he said. "It is not me but the defendants who should be ashamed," he said, touching on the delicate topic of discrimination expressed by health and medical workers and the general public in general toward HIV infected persons. Discrimination "forces a number of people infected with HIV, particularly those living outside of Tokyo to travel a long way to receive medical treatment," he said, adding that small hospitals often refuse to treat HIV-patients.

Etsuko Kawada, mother of Ryuhei, is as outspoken as her son. She recalls how medical specialists in 1985 instructed her to increase the dosage of blood-clotting injections for her son despite suspicions about the product. In a newspaper interview, she said, "I believed them because the Japanese have been taught for decades not to question authority."

At the announcement of the settlement with drug companies, after an official of Green Cross read a statement of apology, someone shouted from the back of the room, "Get down on your knees," to which Etsuko Kawada added: "Admit your responsibility for the crime." Six company executives knelt before their audience, which included millions of television watchers, pressed their heads to the floor and muttered apologies for 10 more minutes.

These days, Kawada is kept busy by requests to give talks to a variety of organisations on his experiences. Kawada dreams of becoming a social studies teacher, perhaps appropriate given the way the Japanese blood scandal has shown how a collusion of business interests and government bureaucrats have proved so fatal. Kawada says, "I believe education is the key to changing the country's current social system, in which the socially strong are favoured at the expense of the socially weak."

Counselling for HIV/AIDS : a key to caring covers counselling service management and policy issues for planners and managers.

Source book for HIV/AIDS counselling training provides guidelines for developing training courses and participatory activities. *Single copies of both books in English available free from UNAIDS Information Centre, c/o WHO, 1211 Geneva 27, Switzerland.*

Guidelines for blood donor counselling on human immunodeficiency virus (HIV) explains how to integrate donor selection, risk assessment and HIV counselling into blood donor programmes for programme planners and staff. *Single copies in English, French and Spanish available free from International Federation of Red Cross and Red Crescent Societies, PO Box 372, CH 1211 Geneva 19, Switzerland or WHO*

Safe blood and blood products is a distance learning course (five manuals) containing guidelines for managing safe blood transfusion and donation (WHO/GPA/CNP/93. *Available in English (order no 1930050) for Sw.fr.84/US$60 (developing countries) or Sw.fr.120/US$84 from WHO/DST, 1211 Geneva 27, Switzerland.*

Practical guidelines for preventing infections transmitted by blood or air in health settings is a briefing paper published by AHRTAG discussing the risks of blood-borne and airborne infections to both carers and patients. Write to HAIN for free copies to developing countries. £5/US$10 elsewhere.

New resources:

TB/HIV : a clinical manual is a clinical management guide for clinicians in resource poor countries. *Available for Sw.fr.12 US/$10.80 in developing countries from WHO*

Starting the discussion : strategies for making sex safer is based on the popular series Let's Teach about AIDS, and provides guidelines for participatory education on HIV, gender and relationships. *Available free to readers in developing countries and for £5/US$10 to readers elsewhere from AHRTAG.*

Updates

Tuberculosis and HIV (Issue 30)
Tuberculosis guide for low-income countries is a handbook providing information for primary level staff. *Single copies are available free from IUATLD, 68 Blvd. Saint-Michel, 75006 Paris, France. (Available in English, French, Spanish)*

The April-June 1996 issue of **Child Health Dialogue** focuses on tuberculosis and children. *For copies, write AHRTAG at 29-35 Farringdon Road, London EC1M, 3JB, United Kingdom.*

HIV, Drugs and Diet (Issue 31)
Eric Van Praag and Joseph H. Perriens, **Caring for patients with HIV and AIDS in middle income countries**. British Medical Journal, August 24, 1996. The authors argue that in some middle-income developing countries, it may be cost effective to use antiretroviral drugs to reduce mother to child transmission or for HIV-positive individuals who were diagnosed early. *Offprints may be requested from HAIN.*

For more information on HIV/AIDS, gender issues, and sexual and reproductive health, you may contact:
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AIDS Action Asia-Pacific
9 Cabanatuan Road
Philam Homes 1104, Quezon City,
Philippines
Telephones: (632) 927-67-60 or 929-88-05
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action

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The international newsletter on AIDS

AIDS action

Special joint issue with CBR NEWS

ue 35
cember 1996–
bruary 1997

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ue 24

ages 2 and 3
Challenging
liscrimination
age 5
HIV fact sheet
age 7
Training exercise:
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Published by
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Disability and HIV

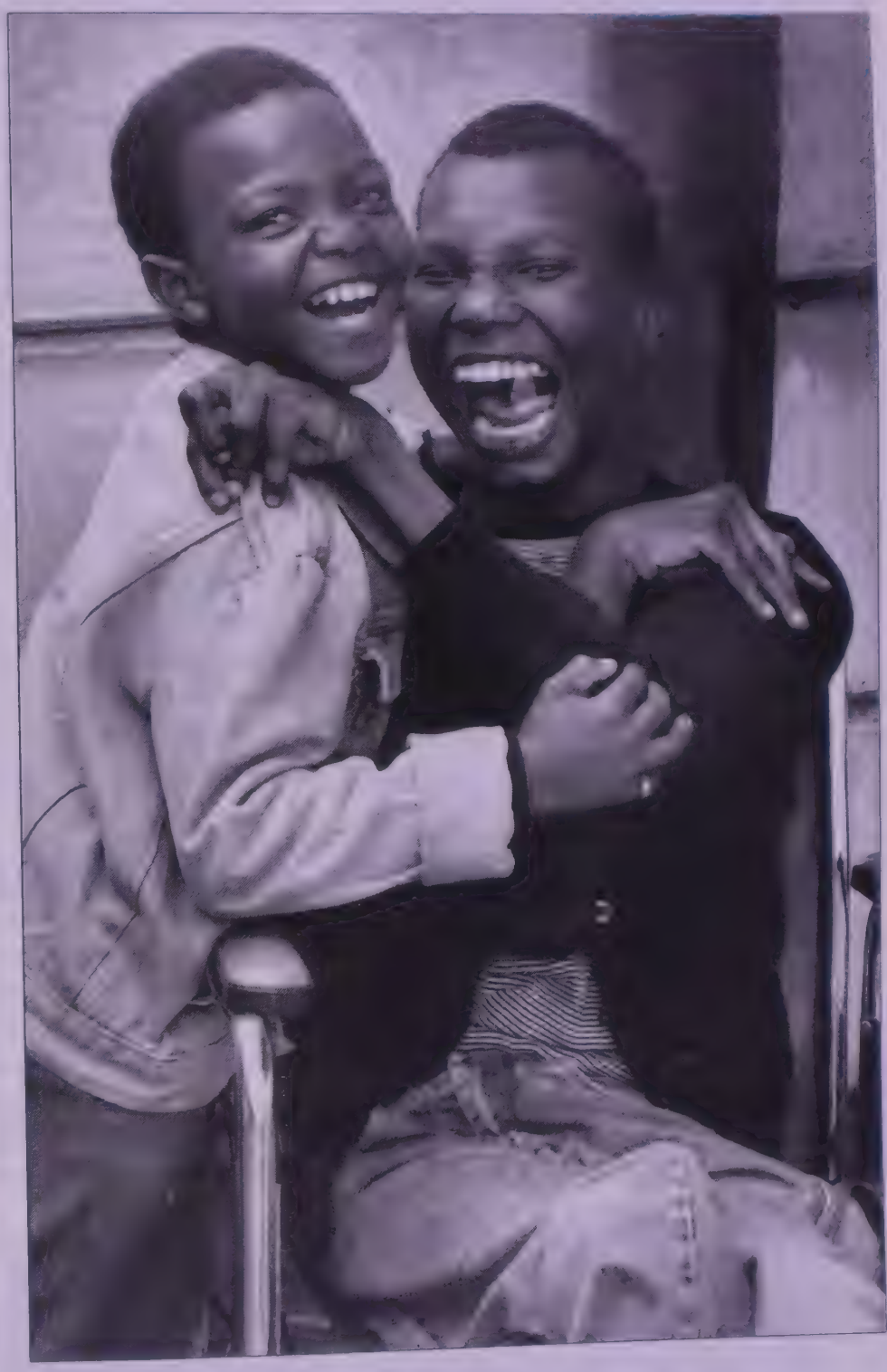
This special issue of *AIDS Action* is published jointly with *CBR News*, the newsletter of AHRTAG's disability programme. Together we hope to raise awareness of disabled people's sexual health needs and to explore how social attitudes to both disability and HIV make people less able to live productive and fulfilled lives.

Many disabled people and people with HIV now have much experience in challenging this discrimination. People are working together to improve their knowledge, challenge barriers they face from others and show other people creative solutions, such as the Brazilian group who describe their project on page 3.

Being disabled can make a person more vulnerable to HIV infection. Disabled people, and their carers and families, need information on sexuality, sexual health and HIV which is appropriate and enables them to take action.

Sadly, information is often not relevant to disabled people's needs or is not available at all. For example, disabled young people may go to separate schools where the teachers feel unable to discuss HIV and sexual health. On page 4 we talk about why this information is necessary and how it can be provided.

This issue of *AIDS Action* and *CBR News* is available on audio-cassette in English and in braille. If you would like these, or future issues on cassette, please write to AHRTAG.



Eric Miller/Panos Pictures

Social attitudes and distorted media images make it hard to accept that disabled people have the same needs, desires and problems as able-bodied people. People make assumptions about our lives. Our futures are often out of our control. We need to know how to protect ourselves against HIV/AIDS like anyone else, with life skills to help us cope with situations that put us at risk of HIV, and training and jobs to improve our economic situation.

A group for disabled young people, Uganda

Disability and impairment

An impairment occurs when part of the body is unable to work fully. This may lead to difficulties in moving, seeing, hearing and learning (sometimes called a mental handicap). Many problems caused by impairments can be overcome by using appropriate aids and equipment, acquiring new skills through education and training, and support from family and community.

Disability occurs where an impaired person's activities are restricted or they are less able to fulfil their potential as human beings because of the barriers caused by society. These can be either through the way that we live, for example by making transport or housing inaccessible, or because other people's prejudices and fears make them discriminate against disabled people. Community-based rehabilitation (CBR) means enabling people with impairments to fulfil their potential within their own community.

HIV-related illnesses can lead to temporary impairment, such as being unable to walk. They can also lead to permanent impairment, such as difficulty in seeing because of eye conditions. People with HIV, even when they are healthy, are also discriminated against which makes it more difficult to find jobs or feel accepted by their community. This treatment by others can 'disable' them.

No accurate statistics exist but a commonly used estimate is that ten per cent of the world's population is disabled. What is certain is that all societies fail to take full account of the needs and rights of disabled people.

Learning from each other

'Barriers set up by other people and by society are often more of a difficulty than the disability itself', says one disabled woman. ***AIDS Action*** *highlights some key challenges.*

Anyone – disabled or not – can become infected with HIV if he or she is exposed to the virus. However, although there are no figures for how many disabled people have HIV, they may be much more vulnerable to infection because of their circumstances. For example, it is often assumed that disabled people do not have sexual feelings or cannot be sexually active, and therefore do not need to know about safer sex.

Abuses of power

Disabled people are often unable to negotiate what they want with other people and may be sexually abused or exploited, as described below by a physiotherapist in Malawi. 'A woman attending the CBR centre for repairs to her wheelchair told me that some men in her village thought that they were helping her by having sex with her. At first she did not understand what was happening and then she tried to say no. Now she tries to avoid this group of men. The women in the village resent her for the sexual attention and do not support her. The village headman ignores the abuse because his son is one of the offending group. No man will consider her as a marriage partner because of what has happened.

'Another woman, who has a learning difficulty, came to the centre with her mother. The anxious mother explained that her daughter had recently given birth to a premature baby in a pit latrine. The woman did not understand what was happening and the baby did not survive. She would not talk about what happened, but her mother suspects rape and feels powerless to protect her daughter.'

Response to risk

Whether involved in disability or AIDS work, organisations need to consider the needs of disabled people who are worried about or have HIV or other sexual health concerns. These needs include:

Appropriate access

HIV, sexual and reproductive health services need to be accessible to disabled people. A deaf person, for example, may need an interpreter to talk to a doctor or a counsellor. People who are paralysed may need special information about sexual

Anita Andersson

Peter Coleridge/Oxfam

ctivity or childbearing. Often people sing wheelchairs cannot easily reach ealth or community centres. Young disabled people may find it hard to get ccess to confidential information ecause their parents or carers are lways with them. People with learning difficulties (mental handicaps) are rarely offered sex education because they are wrongly assumed to be like children who lack sexual desires.

Supportive environments

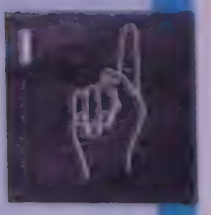
Disabled people are often excluded from community activities, education, training or employment and may even be rejected by their own family or society. Yet disabled people should have the same opportunities as others to experience emotional or sexual relationships and become parents without being pressured or abused. Public education is needed to change people's negative attitudes towards disability and enable disabled people to become more involved in their local communities.

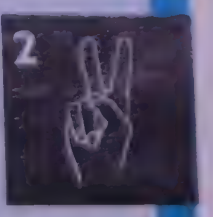
Working together

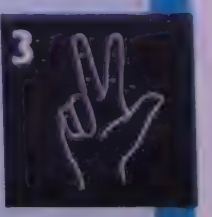
Disabled people and people living with HIV can learn from each other by working together to improve access to information and services and through lobbying for equality and rights. Disabled people's organisations can provide support and information about impairments to people with HIV. HIV workers often have experience in talking about sexuality and can work with staff in disability organisations who may be nervous about addressing such a difficult issue.

The AIDS and Disability Action Project in Canada has built links between AIDS and disability groups. Sharing common experiences helps to encourage more positive social attitudes and also to challenge ignorance about disability in AIDS organisations and prejudice against homosexuality by some disabled people.

Signs in a time of AIDS

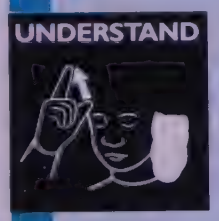






Deaf people face many barriers in communication and it is difficult to find HIV information and projects that respect and are adapted to our language. By language we mean not only Brazilian sign language but also how our methods of communication reflect our community's culture and how we relate to each other and to hearing people. We have to adapt ourselves to a hearing world which is often unwilling to understand and accept differences.

Our project, *Signs in a time of AIDS*, began because several deaf people discovered they were HIV positive and wanted to know more about HIV. In 1994 some hearing people began information sessions in sign language, but deaf people were not involved in decision-making. So we contacted an HIV prevention NGO which was already working with other community groups. Now we have weekly discussion meetings run by deaf people who trained as peer educators to work in the deaf community. As well as using sign language, visual aids and models such as photographs, posters, sex toys – even fruit – are very helpful. It was essential for deaf people to be involved in organising the project. Hearing people rarely understand the deaf community. For example, deaf people are curious to explore the world of sensations. Sex and drugs are an important part of this, and yet these activities are disapproved of and labelled as 'promiscuous' by hearing people. There are very few schools for deaf people in Brazil and they do not teach about sexuality or drug use. We feel that teachers in these schools are frightened of these issues.



The project has already had some successes. For example, some deaf school teachers attended a recent National Meeting of People Living with HIV. In 1997 we will produce a video in Brazilian sign language which will be distributed throughout Brazil and other Portuguese-speaking countries.

Grupo Sinais no Tempo de AIDS, NOSS, Rua Visconde de Pirajá 127/201, Ipanema, 22410-001 Rio de Janeiro RJ, Brazil.

Anita Andersson

Handicap International (HI), a French disability organisation, ran a small rehabilitation centre in Burundi for children who had developmental problems, such as being slow to walk or respond to stimulus. However, the staff noticed that some children did not fit the usual pattern of impairments, and constantly cried. They were initially classified as having learning difficulties but it became clear that the children had HIV and this was causing developmental problems. HI have decided to work with disability and HIV organisations to produce information on appropriate community-based rehabilitation for children who have disabilities because of HIV/AIDS.

Aline Robert, Handicap International, 14 Ave Berthelot, 69361 Lyon, Cedex 07, France.

Left: Information and counselling on HIV and sexual health needs to be accessible to disabled people, for example through sign language or braille.

Right: Disabled people have the right to lead fulfilling lives in their own community – this includes needs related to sexual and reproductive health and sexuality.

Talking about sex and disability

Most of us have concerns about sex and want to talk to someone, but this is often difficult for disabled people.

Carers, families and health workers often focus on disabled people's physical needs and ignore sexual and emotional health. It can be especially difficult for a person with impaired speech or a learning difficulty to talk about their concerns.

A good listener and counsellor is someone who can make people feel relaxed and 'safe', use clear, simple language, avoid being judgmental, and have a good basic knowledge of sex, contraception, HIV and sexually transmitted diseases (STDs). Disabled people themselves, and also health workers, teachers and carers, have an important role to play in discussing these issues.

Learning to love... a personal story

'I was 13 when I suddenly became paralysed. I had to get used to my disability at the same time as dealing with puberty. I was anxious to know if I could make love and be loved, but I was very nervous about it. People thought that because my body was paralysed, my sexual feelings were also paralysed. Then I met a man who was also a wheelchair user. I knew that he was attracted to me, but I believed that I could not have feelings like non-disabled people.

He has made me believe in myself, always focusing on my abilities and not on my disability. I began to realise that a disabled person has options if they are brave enough to take them. Exploring touch with someone you love is wonderful. When disabled people lose sensation in one part of their body, other parts become more sensitive. When I have talked to non-disabled women I realise that what I experience is normal.'

Disabled woman from India

Growing up Parents and health workers do not always accept that sexual feelings are a normal part of growing up for young disabled people just as they are for non-disabled people. Sexual feelings will not go away even if they are ignored. Avoiding discussion of sexual issues and 'protecting' children (especially girls) from sexual knowledge is not helpful. They may be more vulnerable to abuse if they do not understand what is happening and do not feel able to talk to anyone about it.

Young disabled people may have new worries in adolescence. They may be unprepared for leaving home and working, mixing with others or forming relationships and feel great anxiety about their future.

Life changes People who become disabled as adults (for example, through illness, including HIV, or injury) may feel low self-esteem and a sense of failure because they are unable to continue working or having a sexual relationship. Many men in particular say that they are concerned about their sex life.

Women may face additional problems. A woman may worry about whether her husband will stay with her or whether she can have children. Disabled women, and also HIV-positive women, can have children yet they are often under pressure not to. They often have little access to reproductive health information and are forced to be sterilised or have abortions without their consent.

Counselling and support

People with different impairments need different types of information, counselling or practical support. For example, a person with physical or sensory difficulties will need a different approach from one with learning difficulties. However, the following guidelines are helpful:

- Provide information and services on avoiding unwanted pregnancies, STD and HIV prevention and sexual abuse.
- Acknowledge anxieties and do not pretend that they are unimportant.
- If disabled people feel that they are unattractive, help them to identify features they like about themselves and to feel more comfortable about their impairment by wearing suitable clothing or making aids and appliances look attractive.
- Identify places where they can meet people, including others with similar impairments.
- Help people overcome feelings of shyness and insecurity or difficulties in talking to their partner by discussing sensitive issues in role plays.

Do not assume that you know what the problem is. Listen carefully to what people say and try to find practical and supportive ways to help them. It is difficult for a non-disabled person to understand the feelings of disabled people. It may be helpful to involve other disabled people to explore feelings more fully, give appropriate information and to provide a positive role model.

These ideas are explored at greater length in Challenging disability, a guide for frontline social workers in Africa, Modules 7 and 8, *by Helen Jackson, ILO Southern Africa Regional Office, 1992.*

Although now out of print, AHRTAG can send copies of the relevant pages free to readers in developing countries (one copy per request).

HIV fact sheet

What is HIV?

HIV stands for **H**uman **I**mmunodeficiency **V**irus. HIV only infects humans. It attacks the body's immune system, which protects the body against illness.

Soon after being infected, some people may suffer flu-like symptoms for a few weeks. Otherwise there are no signs of early HIV infection. However, the virus remains in the body and can be passed on to other people. Once infected, a person is infected for life and there is no cure. No traditional or Western medicine has been been proven to kill the virus. Some people remain healthy for many years, depending on access to treatments, nutrition and lifestyle.

What is AIDS?

AIDS stands for **A**cquired **I**mmune **D**eficiency **S**yndrome. Getting (acquiring) HIV infection leads to a weakened (deficient) immune system. This makes a person with HIV vulnerable to a group of illnesses (syndrome) that a healthy person without the virus would be unlikely to be affected by (opportunistic infections).

These illnesses include rare cancers and eye, skin and nervous system conditions as well as tuberculosis, coughs and diarrhoea.

How is HIV transmitted?

HIV is found in an infected person's blood (including menstrual blood), breast milk, semen and vaginal fluids.

- During unprotected sexual intercourse, HIV can pass from someone's infected blood, semen or vaginal fluids directly into another person's bloodstream, through the mucous membranes lining the inside of the vagina, penis or rectum.
- HIV can be transmitted by HIV-infected blood transfusions or contaminated injecting equipment or cutting instruments.
- HIV can be passed to a baby during pregnancy, delivery and breastfeeding. About a third of all babies born to mothers with HIV become infected themselves.

What is unsafe or high risk behaviour?

This is doing something that involves a high risk of infection for you or someone else. Most people do not know who has HIV and who does not, including themselves, so the following activities are high-risk:

- having penetrative vaginal or anal sex (where the penis enters the vagina or anus) without using a condom. Men can infect both male and female partners through unprotected anal sex
- using unsterilised needles and syringes, or cutting instruments, on yourself or someone else, that are likely to be contaminated by another person's blood
- receiving an infected blood transfusion.

Is disability linked to HIV?

Disabled people are just as much at risk of HIV infection as anyone else if they have unprotected sex or share contaminated injecting equipment. However, they may be more vulnerable because of sexual abuse or lack of information.

What is safer sex?

Safer sex is any sexual activity which does not involve semen, vaginal fluids and blood entering another person's body or coming into contact with broken skin, such as:

- non-penetrative sex – stimulating your own or your partner's genitals (masturbation), thigh sex, massage or kissing
- using a condom for vaginal or anal sexual intercourse.
- Oral sex (mouth contact with male or female genitals) is less risky than unprotected vaginal or anal sex.
- No sex (abstinence) is safe.

What is an HIV test?

An HIV test detects antibodies to HIV in the blood. These are produced by the immune system in response to infection with the virus.

If there are no antibodies, the person is antibody negative (seronegative or HIV negative). The test result may be negative if the person has been infected only recently, because it can take up to three months from the time of infection for the antibodies to develop. This is called the 'window period'. Anyone who might have become infected in the last three months should take a second test three months after the first test.

A person should always have counselling before and after an HIV test. HIV tests should never be carried out without the person's informed consent.

How is HIV not transmitted?

The virus can live only inside a living human body and survives for just a few hours outside the body.

- HIV cannot be transmitted through saliva, tears, vomit, faeces and urine, although very small amounts of the virus have been found in these fluids. HIV has not been found in sweat.
- HIV cannot pass through unbroken skin and is not spread through casual contact such as touching someone with HIV, or something they have used; sharing eating or drinking utensils; or using the same toilet seats or washing water.
- Nursing or caring for someone with HIV is not risky if the person follows sensible precautions such as disposing of sharp needles safely and keeping cuts covered.
- HIV is not transmitted by mosquitoes or other blood-sucking insects. Most insects do not pass blood from one person to another when they bite humans. The malaria parasite enters the bloodstream in mosquito saliva, not blood.

Keeping safe, feeling healthy

Life skills education for young people with learning disabilities can help them to develop skills and self-confidence.

All too often young disabled people are treated with pity or misplaced sympathy, or, even worse, their needs are ignored altogether. This is especially true for people with learning difficulties. Adults normally make the decisions which affect these young people's relationships, sexuality and bodies.

It can be difficult to discuss sex with people with learning difficulties. Parents may want to 'protect' their children and feel that they are not interested in sex because they develop differently to other young people of the same age. For example, they may find it difficult to understand that films or advertisements are not the same as people's everyday lives. They need support in learning about appropriate behaviour in public, with their friends or families, or in private by themselves.

They need to develop their confidence and self-esteem, as well as their skills to negotiate sex if they want it or to say no if they don't. Some people think that sex education encourages young people to experiment with sex, but in fact research shows that they make wiser decisions about sex if they have information and can practise the skills to put their choices into action.

Learning to live

In the Netherlands a sex education project for young people with learning difficulties focuses on three themes:

- **myself as a person** – photos and drawings showing different stages of physical development and how to look after your body
- **myself in relation to others** – different types of relationship and lifestyle
- **myself in relation to society** – understanding private and public behaviour including sexual feelings and actions.

Using photos and drawings helps teachers and parents to discuss many different aspects of sexuality. The aim is to promote self-esteem and a positive self-image and express thoughts and feelings about sex. Games or very simple role plays are used to practise communication and assertiveness skills.

These games and activities are very challenging for both adults and teachers, but as a young person with a learning difficulty said after doing this course, 'Talking about sex is fun. Now I can ask my teacher all kinds of questions. I am in love now and I know what to do.'

With thanks to Doortje Braeken, Rutgers Foundation, Netherlands.

Different aspects of life skills education for people with learning difficulties

Feelings and emotions
Understanding and expressing feelings, such as fear, happiness, sadness, responding to others' moods
How I look and how others see me
Clothes I like and dislike, choosing colours and hairstyles I like
Understanding my body
Personal hygiene, sex and development, pregnancy, parenthood, delaying sex
Developing self-confidence
Using and enjoying my senses, practising speaking up for myself and being assertive about my decisions
Keeping and feeling safe and healthy
Touches that I like and dislike, words which make me feel good or bad
Relationships with others
My family and my home, friendships, differences between strangers and friends, caring for other people

Source: Cooper, D; Sexuality: Bulletin on sexuality and personal relationships, 53, January 1996

Check your attitudes

This activity aims to encourage people to think more deeply about their attitudes towards different people's sexuality.

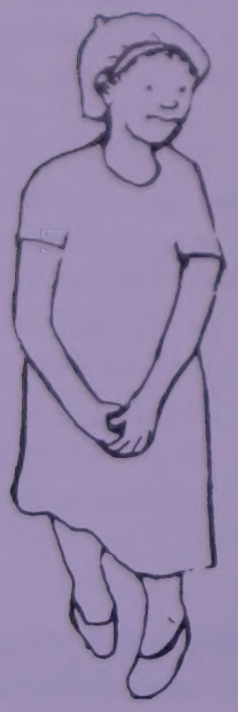
It is often difficult to talk about sexuality and relationships. We have our own beliefs about what is 'right' and 'wrong' and may feel awkward discussing this in public. This activity uses pictures of different people to encourage discussion about common assumptions and to explore whether these are true or not. It allows us to discuss our beliefs without having to disclose personal experiences.

Before you start

The pictures you use should reflect the local situation and stimulate discussion about common attitudes, for example that disabled people are not sexually active. Think about what attitudes exist locally and what people in your group may feel able to discuss. Draw different pictures, or cut photographs from newspapers. Here are some examples of pictures and questions but you will need to choose ones which are appropriate for your situation.

- Explain that the activity aims to help us think more about how we see other people and to question our own assumptions.
- Invite people to look at each picture and answer the following questions:
  What work do you think that this person does?
  Is this person married?
  Where does this person meet other people socially?
  Do you think that this person has children?
  Would they like to have children?
  Do you think that this person has sex? If so, with whom?
  What concerns might they have about sex or relationships?
  Who does this person talk to when they are worried about their relationships or sexual health?
- Once people have talked about these issues, the facilitator should encourage discussion about whether people are like these pictures in real life.
  How do assumptions made about people affect their daily lives?
  How can we challenge attitudes which limit people's opportunities to have fulfilled lives?

With thanks to Tracy O'Reilly.



Sources: FCI, Inc/USA, ILO and WHO/Malaria Consortium

AHRTAG wants to hear from you...

If you work on disability and AIDS write to us and share your experiences. We would like to hear more about projects similar to the ones featured in this special issue.
If you found this issue on disability and HIV useful and would like to continue to receive *CBR News* or *AIDS Action*, please write to AHRTAG.

Future issues of AIDS Action

Issue 36 and 37 (March – August 1997): 20-page double issue on **sexual and reproductive health** including practical training and education materials.

Issue 38 (September – November 1997): **health workers and HIV** – impact of HIV on health services, issues affecting HIV-positive health workers and support for carers.

Issue 39 (December 1997 – February 1998): **learning from success** – what is needed to make HIV prevention programmes work.

If you would like to contribute to these issues – or any others – please send articles to AHRTAG.

RESOURCES ON DISABILITY

Community-based rehabilitation, CBR, for and with people with disabilities describes what CBR is and gives ideas for sustainable CBR programmes. *Single copies are available free from the Vocational Rehabilitation Branch, ILO, 4 Route de Morillons, CH-1211 Geneva 27, Switzerland.*

Disabled village children: a guide for community health workers, rehabilitation workers and families has information on disability and how to set up CBR programmes using simple language and illustrations. *Single copies are available for £7 plus postage and packing in English, French and Spanish from TALC, PO Box 49, St Albans, Herts AL1 5TX, UK. Other languages including Arabic, Hindi, Portuguese, Swahili and Urdu available from Hesperian Foundation, Box 1692, Palo Alto, CA 94302, USA.*

Essential CBR information resources is a list of nearly 120 key free or low-cost publications and articles on CBR. *Available free to developing countries (£5/US$10 elsewhere) from AHRTAG.*

Everything you ever wanted to know about safer sex book is an illustrated booklet on sex, contraception and HIV prevention for people with learning difficulties. *Available for £4 (book) and £7 (tape) from People First, 207-215 King's Cross Road, London WC1X 9DB, UK.*

ORGANISATIONS

Disabled People's International (DPI) is the world-wide co-ordinating body for disability organisations run by disabled people with the goal of achieving equal rights. *DPI, 101-7 Evergreen Place, Winnipeg, Manitoba R3L 2T3, Canada.*

Disability Awareness in Action is an international information network supporting disabled people's human rights. *Disability Awareness in Action, 11 Belgrave Road, London SW1V 1RB, UK.*

RESOURCES ON HIV AND AIDS

Essential AIDS information resources lists 125 key free or low cost resources on HIV and AIDS for developing countries. *Available free to developing countries (£5/US$10 elsewhere) from AHRTAG.*

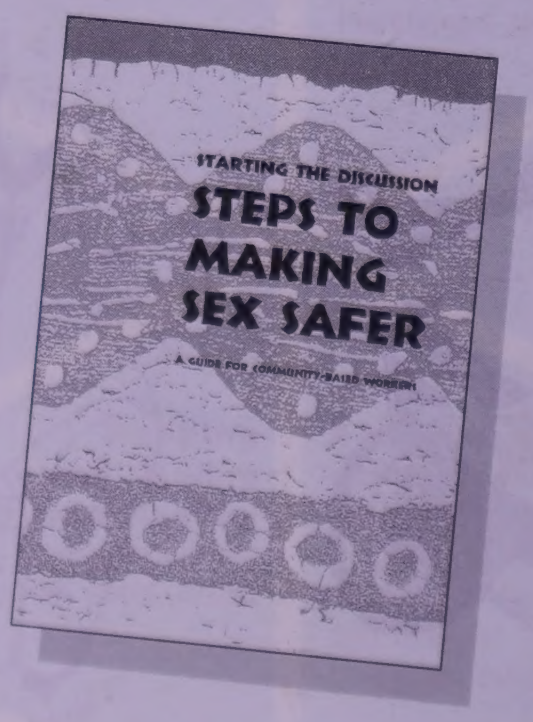
Strategies for Hope is a series of booklets describing successful case studies and practical strategies on HIV care and prevention projects. *Available from TALC. (Booklets cost £1.95 and £2.50 – contact TALC for price details.)*

AHRTAG and its partners can put readers in touch with local HIV prevention and care organisations.

NEW PUBLICATION

Starting the discussion: steps to making sex safer provides ideas for training activities to enable people to participate in discussion about HIV prevention and making sex safer.

This guide is based on an earlier series of booklets *Let's teach about AIDS. Available free to developing countries (£7/US$14 elsewhere including postage) from AHRTAG.*



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